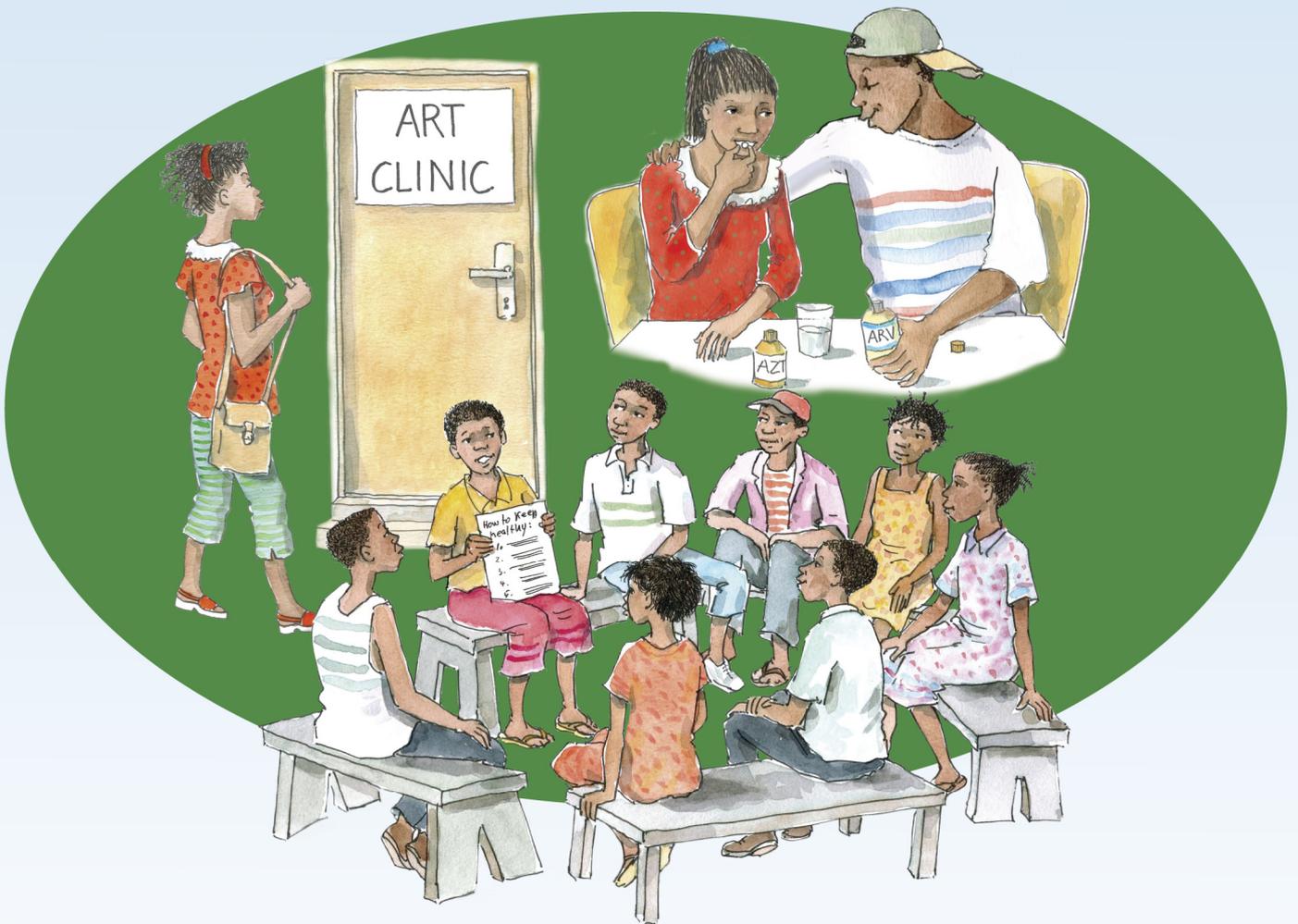




# Adolescent HIV Care and Treatment

A Training Curriculum for  
Multidisciplinary Healthcare Teams

## TRAINER MANUAL



March 2011





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## **Abbreviations and Acronyms**

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3TC	Lamivudine
ABC	Abacavir
ADHD	Attention deficit hyperactivity disorder
ALHIV	Adolescent(s) living with HIV
ALT	Alaninaminotransferase, a liver enzyme
ANC	Antenatal care
ART	Antiretroviral therapy
ARV	Antiretroviral
AST	Aspartate transaminase or aspartate aminotransferase, a liver enzyme
AZT	Zidovudine
BMI	Body mass index
BSE	Breast self examination
CAB	Client/consumer/community advisory board
CD4	T-lymphocyte CD4 cell count
CHIPS	Collaborative HIV Paediatric Study
CMV	Cytomegalovirus
COCs	Combined oral contraceptive pills
CrCl	Creatinine clearance
CTX	Cotrimoxazole
d4T	Stavudine
ECPs	Emergency contraceptive pills
EFV	Efavirenz
FAO	Food and Agriculture Organization
FBC	Full blood count
FTC	Emtricitabine
GNP+	Global Network of People Living with HIV and AIDS
GYCA	Global Youth Coalition on HIV/AIDS
HBsAg	Surface antigen of the Hepatitis-B-Virus (HBV)
HIV	Human immunodeficiency virus
HIV VL	HIV viral load
ICW	International Community of Women Living with HIV
IMAI	Integrated Management of Adolescent and Adult Illness
INH	Isoniazid
IPT	Isoniazid preventive therapy
IRIS	Immune reconstitution inflammatory syndrome
IUD	Intra-uterine device
LAM	Lactational amenorrhea method
LFT	Liver function test
LPV/r	Ritonavir boosted lopinavir
MoH	Ministry of Health
MTCT	Mother-to-child transmission (of HIV)
NNRTI	Non-nucleoside reverse transcriptase inhibitor
NRTI	Nucleoside reverse transcriptase inhibitor
NVP	Nevirapine
OIs	Opportunistic infections

ORS	Oral rehydration solution
PCOE	University Teaching Hospital's Department of Paediatrics HIV Centre of Excellence in Zambia
PI	Protease inhibitor
PITC	Provider-initiated HIV testing and counselling
PMTCT	Prevention of mother-to-child transmission (of HIV)
POPs	Progestin-only oral contraceptive pills
QA	Quality assurance
QI	Quality improvement
RFT	Renal function test
sdNVP	Single-dose nevirapine
SRH	Sexual and reproductive health
STI	Sexually transmitted infection
TB	Tuberculosis
TDF	Tenofovir
TSE	Testicular self-examination
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
WHO	World Health Organization

## Foreword

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Despite a 25% reduction in HIV incidence in Zambia between 2001 and 2009, HIV prevalence for the population as a whole was still estimated to be 13.5% in 2009<sup>1</sup>. In 2009 alone, 59,000 adults were infected with HIV as well as 17,000 children. UNAIDS estimates that a total of 120,000 children between the ages of 0–14 years are now living with HIV in Zambia. Of the children with perinatally acquired HIV (that is, HIV infection acquired through mother-to-child transmission of HIV [MTCCT]), without treatment about half will die before their 2<sup>nd</sup> birthday. According to UNICEF's *Children and AIDS: Fifth Stocktaking Report, 2010*, of the 120,000 children living with HIV, about 59,000 are in need of ART. Of those 59,000, 36% are receiving it. Given this increased access to paediatric HIV care and treatment, more and more perinatally infected children are living longer and reaching adolescence and adulthood.

In addition to adolescents with perinatally acquired HIV, many adolescents have acquired HIV during their youth. Prevalence figures for Zambia's youth are sobering: 8.9% of young women (15–24 years of age) and 4.2% of young men are infected with HIV — many, if not most, acquired HIV behaviourally, primarily through sexual transmission.

Given the prevalence of HIV in Zambia's adolescent population (those between the ages of 10–19 years), the Ministry of Health (MoH) is committed to developing HIV services that specifically serve the needs of this population. Whether behaviourally or perinatally infected with HIV, adolescents living with HIV (ALHIV) face unique health, adherence, and psychosocial issues and challenges. Programmes and clinical services need to be youth-friendly to attract and retain adolescent clients in care. Zambia already has successful models of adolescent HIV care and treatment services (such as the Adolescent HIV Clinic at University Teaching Hospital PCOE in Lusaka), that can be scaled up nationally. But scaling up depends on making a commitment to adolescent HIV services and continuously improving the knowledge and skills of healthcare workers so that they can best address the specific needs of adolescent clients. This “Adolescent HIV Care and Treatment Training Curriculum for Multidisciplinary Healthcare Teams” represents a key step in the MoH's commitment to ensure the rollout of HIV-related services that truly serve the needs of ALHIV. Young people are our future!

# Trainer Manual Introduction

## Section 1: Overview of the Training and Trainer Manual

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### Goal of Trainer Manual

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The goal of this 8-day training is to equip healthcare workers with the knowledge and skills to plan, implement, monitor and evaluate services for adolescents. The training is primarily classroom-based and content-focused, but also includes 2–2.5 days of a supervised clinical practicum.

This Trainer Manual was developed to support planning and implementation of the course. Each module provides technical content along with guidance on how to teach that content. In addition, this Introduction to the Trainer Manual includes sections on “Trainer Toolkit” and “Tips on Training Methods” to help trainers hone their facilitation skills to maximise opportunities for interactive learning.

**Note:** Blocks of text in the Trainer Manual surrounded by a *dashed border* do NOT appear in the Participant Manual.

### Icon Key

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The Trainer Manual includes the following symbols (icons):



**Trainer instructions:** Guidance for the trainer.



**Make these points:** Key concepts to emphasize.



**Total session/module time:** Estimated time needed for each module or session. All times listed are suggested and subject to change depending on participant learning needs.



**Advance preparation:** Planning and preparation for a session or exercise that should be undertaken in advance.



**Methodologies:** Training methods used in the module, for example, large group discussion or role play).



**Materials needed:** Material needed to teach the module, for example, flip chart and markers).



**References and resources:** The list of guidelines, books, journals and other documents that contributed to the content of the module. These may be useful to trainers or trainees who want more information on a particular topic or issue.



**Key points:** A summary of the material presented in the module. The key points for each module should be reviewed with participants at the end of the module.

## **Components of this Training Package**

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You should become familiar with all components of this training package: the Trainer Manual, the Participant Manual and the accompanying PowerPoint Slides.

### **Trainer Manual**

Each of the 15 modules in the Trainer Manual includes technical content as well as Learning Objectives, Trainer Instruction — including session and module times, Make These Points, Advance Preparation, Methodologies, Materials Needed, References and Resources, Key Points. Each session and exercise lists the estimated amount of time estimated required for that activity.

Before facilitating the training, you should read through each of the modules, study the technical content — including the appendices — to ensure you understand it, review the exercises closely, take note of exercises that require advance preparation and anticipate participant questions.

- “Trainer’s Instructions” and “Make These Points” refer to the content immediately following the instructions box and preceding the next instructions box.
- Suggested questions are often provided to help you engage and draw responses from participants. These questions are in italics.
- The exercises in each module include large group discussion, case studies, small group work, games and role plays. Instructions, including recommended time frames, for each exercise can be found in the exercise instructions. In preparing exercises, review “Section 3: Tips on Training Methods”, which starts on page 23.
- Be flexible. Be ready to change exercises or the order of the agenda to adapt to the needs of participants.
- Become familiar with the PowerPoint slides prior to the training by reviewing them several times and comparing with the module content.

**Advance preparation and practise will help keep sessions to the recommended time and increase confidence.**

## **PowerPoint slides**

The PowerPoint slide sets were developed to facilitate the presentation and discussion during training. When presenting the slides, you should have the Trainer Manual nearby for reference.

## **Participant Manual**

The Participant Manual contains the same technical content as the Trainer Manual. But the Participant Manual does not include the detailed instruction for each exercise (instead, it includes abbreviated instructions for each), nor does it include the Methodologies, Materials Needed, References and Resources, Advance Preparation, Modules/Session Time, Trainer Instructions or Make These Points boxes.

## **Pre-test/Post-test**

Module 1 contains the Pre-test and Module 15 the Post-test. The Pre-test/post-test is designed to assess knowledge gained as a result of the training. Both tests are exactly the same, except that one is administered before the start of training and the other at the end of training.

Participants do not need to write their names on either the pre- or the post-test, it can be completed anonymously. But, as you will need to compare each participant's post-test score with their pre-test score, ask that each participant put a number at the top of the pre-test. This can be any number (for example, a child's birth date or a phone number) and it can also have any number of digits. But participants should remember this number, as they will need to record the exact same number at the top of their post-test. Suggest that they write this number on the inside front cover of their Participant Manuals, so that they cannot forget it.

The answers to the pre-test/post-test appear in Module 15. The pre-test/post-test is discussed further in Session 1.3, in Module 1.

## **Course Schedule**

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“Adolescent HIV Care and Treatment Training Curriculum for Multidisciplinary Healthcare Teams” was developed as an 8-day course, including the classroom sessions and clinical practicum. “Appendix 1A: Sample Training Agenda” in Module 1 includes a suggested training agenda.

# Trainer Manual Introduction

## Section 2: Trainer Toolkit

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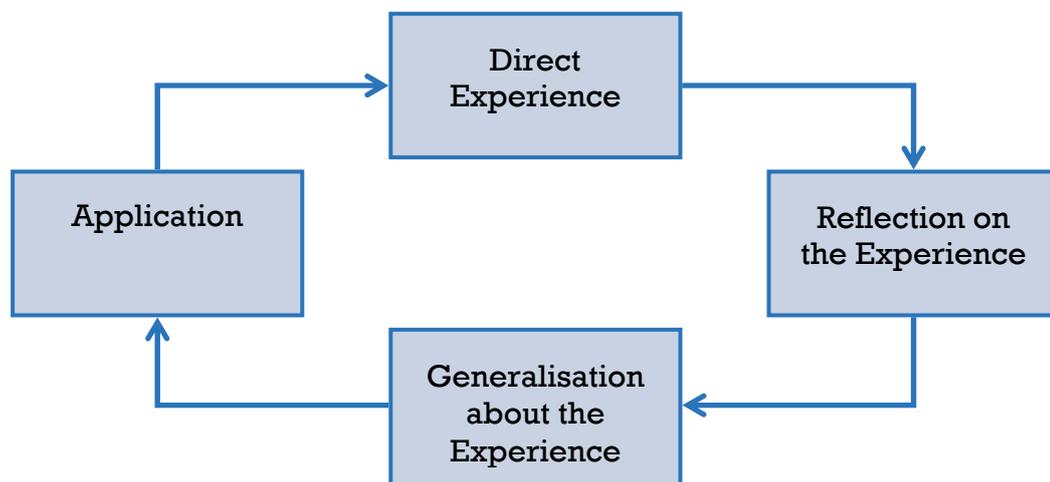
### Adult Learning and Experiential Learning Cycle

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Adults learn differently than children, bringing their abilities and life experiences to the training. The key to successful training sessions is the active participation from the group through the sharing of these life experiences, insights and perspectives. You, as the trainer, show respect for participants' experience by asking them to share ideas, opinions and knowledge and by recognising that they are a good resource. Important principles of adult learning to consider are highlighted in "Principles of Adult Learning" on page 10.

The premise of adult learning is presented in "Figure 1: The Experiential learning cycle". In experiential learning, participants are encouraged to experiment with or try different and new ways of thinking and behaving, thereby exploring more effective ways to solve problems and apply solutions. Encourage discussion among participants throughout the process; interactive communication underpins all stages of experiential learning. Through this interactive communication, participants share the responsibility of learning with the trainer.

**Figure 1: The Experiential learning cycle**



Adapted from Gormly, W. and McCaffery, J. (1982). Design Components of an Experiential Training Session. <http://www.icarzcu3.gov.in/kvk/technical/4.pdf>

#### **The 4 stages of the experiential learning cycle are:**

**Direct experience** — During this training, the direct experience is represented by activities such as the exercises and small group activities.

This “experience” provides the foundation of the learning process, but is only the beginning. In this stage, trainers encourage participants to become involved in the activity by seeing, observing or saying.

**Reflection on the experience** — This stage is often marked by the trainer posing questions that focus on what happened in the “experience”. The trainer asks the participants to think back and reflect on the activity and identify what they thought, felt, or how they behaved during the experience. The focus should stay on what occurred as opposed to why it occurred.

**Generalisation about the experience** — Whereas the reflection stage examines what happened, the generalisation stage is concerned with why it happened. The trainer will ask questions such as “What was learnt?” or “Of what we learnt in this activity, what can be transferred to other situations?” In this manual, this stage usually takes place in the “debrief” portion of the exercise. Debriefing is crucial because it helps solidify what was learnt and makes it more likely that the participant will think critically about the experience and gain as much from it as they can.

**Application** — The final stage in the cycle is often difficult to realise fully in training, but progress can be made by helping participants identify areas where they can apply what they have learnt. It should be emphasized that the goal of experiential learning, and this training in particular, is the personal application of skills and knowledge.

Experiential education, through the implementation of the experiential learning cycle, is a more effective model than the traditional or formal classroom approach because it responds to the needs of the adult learner. More importantly, experiential education teaches adults how to learn and think; a process by which continued personal growth and development is possible. For this reason, 2–2.5 days of hands-on, clinic-based practicum is a central part of the training. Learning will be solidified by the application of classroom-based skills during the practicum experience and by the continued practice of adolescent-specific services at home facilities.

## **Principles of Adult Learning<sup>2</sup>**

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**Adults need to feel comfortable and may be reluctant to take risks.**

- Create a comfortable and safe learning environment and utilise facilitation methods that will reassure participants that contributions will be received respectfully.
- Respect participants who are reluctant to speak in large groups or take an active role in learning activities. Support them in sharing their experiences in other ways during the training, such as within small group activities.

- Build the relationship between you and participants by sharing experiences and commitment. Trainers should be willing to take similar risks to those asked of the participants.
- As the trainer, you should be accountable — willing to state how you know something. If you do not know something, you should state so, while making a commitment to find the answer.

### **Adults need to actively participate in their learning.**

- Give participants opportunities to identify learning objectives and to participate in planning their education. Ask them what they hope to learn and take away from the training.
- Involve participants in interactive activities early in each session.
- Build a sense of belonging to a team by encouraging participation.

### **Adults have a wealth of life and work experiences.**

- Provide opportunities for participants to share their knowledge and experiences with the group and to solve problems with others.
- Encourage participants to share personal experiences. Sharing your own experiences and stories gives permission for others to do so.

### **Adults value practical information that they can use.**

- Develop content that will provide knowledge and skills that participants can make use of right away and point out the immediate usefulness of information presented.
- Provide opportunities for participants to practise what they are learning and to address feelings, as well as ideas and actions.

## **Principles for Trainers<sup>3</sup>**

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Given the principles of adult learning, your role as the trainer is to assist or facilitate the learning experience. The good trainer creates a winning situation in which both the trainer and participants can successfully accomplish the training outcomes. Your role is to identify and use participants' professional and personal life experiences as resources for learning. You may be the content expert but you are there more to clarify and fill in the gaps in participants' knowledge rather than to lecture on a body of information. The goal is to facilitate learning and create an environment where participants are comfortable asking questions. It is essential to identify participants' needs and goals and incorporate them into the training objectives. The Pre-test will aid in this process, as will Exercise 1: Getting to know each other, in Module 1.

You are also responsible for organising and pacing the content so that it meets the participants' needs and understanding. In addition, you should:

- Accept each participant as a person of worth and respect her or his feelings and ideas.

- Seek to build relationships of mutual trust and helpfulness by encouraging cooperative activities.
- Express your own feelings and contribute resources as a co-participant and member of the group in the spirit of mutual learning.
- Encourage spontaneous questions, comments and rebuttals.
- Show respect for differing opinions and values, and for repetitive questions.
- Respond to the expression of thoughts and feelings by participants in the classroom.
- Motivate participants by creating conditions that help them recognise their need to know.
- Organise and make available a wide range of resources for learning.
- Bring to the classroom a sense of humour and enthusiasm about the subject and teaching methods.

## **Roles of the Trainer**

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1. *Trainers are the standard-setters for the discussion.* As the trainer, you must stay focused and alert, interested in the discussion and the learning that is taking place. You create the standards of communication by looking around the room at all participants, listening closely and encouraging contributions from all.
2. *Trainers make the training environment a priority.* You are in charge of deciding everything — from how the tables and chairs are set up to where small group exercises will take place, among other logistical issues. You are also responsible for judging how the physical environment of the training affects the atmosphere and then making changes in the physical environment as needed.
3. *Trainers are mindful of timing issues.* It is easy to over-schedule activities and not incorporate enough down time for participants. Avoid planning emotionally intensive activities directly before or after a meal. Always allow for activities to take longer than expected.
4. *Trainers are responsible for explaining the purpose of the exercise or discussion and its significance to the group.* It is important to clearly state the goal and function of each activity. Also, let the group know the expected time that will be spent on each activity.
5. *Trainers make use of various techniques and tools to keep the discussion moving when tension arises or discussion comes to a halt.* You must be prepared with tools to keep participants engaged and learning.
6. *Trainers are responsible for paying attention to group behaviours.* You should be observant of verbal and non-verbal cues from the group and take appropriate actions to meet said or unsaid needs.<sup>4</sup>
7. *Trainers are responsible for ensuring confidentiality in the learning environment.* During training participants share patient case studies as well as stories of how they, their colleagues or managers have handled a particular scenario in the workplace setting. Typically these stories are brought up to illustrate a lesson learned or as an example of current practice. Stress to participants that this body of knowledge needs to

remain confidential and ensure that you as a trainer role model that confidentiality.

## Trainer Preparation Checklist

**Table 1: Trainer checklist**

✓ Complete the following before starting each module
Read manual objectives, technical content and teaching exercises.
Prepare for each of the exercises according to Trainer Instructions.
Obtain and organise the materials needed.
Read the content and suggestions for facilitating group discussion. Add your own questions or tips that will help you engage participants and ensure key messages are discussed.
Review the PowerPoint slides and become familiar with their content.
Practise! It is not always easy to explain group exercises or to draw responses from an audience. Be prepared by thinking ahead about developing strategies. For complicated exercises or discussions, consider co-facilitation.
Have a plan for monitoring time and keeping on schedule.
Have a plan for coping with a difficult or disruptive participant.
Choose a technique for creating small groups. If this is done multiple times during the day, choose different methods for each instance unless specified that groups should remain the same.
Learn what you can about participants before the training (for example, their worksite, role, responsibilities, skills, and experience). This effort should continue throughout the training.

## Tips for Co-training

When planning a module presentation with a co-trainer, discuss the following questions to help clarify your roles:

- *Which parts of the module would you like to be responsible for?*
- *Which parts would you like your co-trainer to handle?*
- *What is your teaching style? How do our teaching styles differ? What challenges might arise? How can we ensure we will work well together?*
- *What signal could you use for interrupting when the other person is presenting?*
- *How will you handle staying on task?*
- *How will you field participant questions?*
- *How will you make transitions between each of your presentations?*
- *How will you get participants back from breaks in a timely manner?*

## Co-training Checklist

**Table 2: Co-training checklist**

✓	<b>Preparation</b>
	Decide who will lead and teach each session of each module.
	Decide on a plan for staying on time including how you and your co-trainer will signal each other when time is up.
	Decide together how to arrange the room.
✓	<b>During training</b>
	Support your co-trainer when she or he is presenting by paying attention. Never correct your co-trainer in front of the group.
	Ask for help from your co-trainer when you need it, such as when you do not know the answer to a question or if you are not sure of something.
	Sit somewhere so that you and your co-trainer can make eye contact but where the person who is presenting has the spotlight.
✓	<b>After training</b>
	Discuss what you thought went well and what could be done better; take notes so that you will remember the next time.
	Discuss ways to help support each other during future trainings.

## Adolescent Co-trainer

Throughout this training you will notice that there are references to the adolescent co-trainer. The role of the adolescent co-trainer is to provide an adolescent perspective to the technical content presented in the course and the exercises, including discussion of case studies. The adolescent co-trainer is not necessarily expected to be a content expert, but rather is there to provide input on adolescent “realities”, services and service provision from the perspective of the adolescent client. The interaction between trainer and adolescent co-trainers during training sessions can provide a helpful model to participants on how to interact with adolescents in the clinic setting and how to work with Peer Educators in the workplace.

Where possible, aim to have a team of 2–4 adolescent co-trainers. Ideally the team should include both a male and female, and a combination of at least one person with perinatally acquired HIV and one with behaviourally acquired HIV. But, of course, such a mix may not always be possible.

### Recruiting adolescent co-trainers

Sites that have an established adolescent Peer Educator programme will be able to recruit adolescent co-trainers from this group of young people.

In the absence of an adolescent Peer Educator programme, adolescent co-trainers can be recruited from other volunteer groups (if the clinic has a cadre of volunteers), a support group, or youth living with HIV

associations. Alternatively, the multidisciplinary team may be involved in selecting adolescent role models from their own client rolls. It may also be possible to engage Peer Educators from other clinics to take on the role of adolescent co-trainer. Adolescents who are minors will need parental consent to be engaged in this work.

### **Adolescent co-trainer qualities**

The adolescent co-trainer is someone who is living with HIV and enrolled in HIV care and treatment. In most cases the adolescent co-trainer is a young person who is at least 16 years of age, preferably at least 18 years of age or older. The adolescent co-trainer must be someone who has demonstrated good adherence to their own care and treatment, is mature, articulate and able to speak comfortably with adults.

Adolescents have many of their own responsibilities, so the role of the adolescent co-trainer may need to be scheduled around these responsibilities, especially for adolescents still in school or who work during the day. Recruiting a team of 4 adolescent co-trainers allows the trainer to ensure the maximum level of support by allowing adolescents the flexibility to balance the time needed for this training with their other commitments.

Adolescent co-trainers may be interested in the job either because of the professional experiences it brings or simply for the opportunity to “give back”.

### **Training of adolescent co-trainers**

All adolescent co-trainers will need a ½ to 1 day training before they would be expected to function in their role as a co-trainer. The training should include a summary of this course, a description of the role of the adolescent co-trainer, and include role play (on, for example, on how to assist participants with exercises, how to respond to discussion questions from the trainers, how to respond appropriate in the unlikely event that a participant says something that the adolescent co-trainer finds upsetting, etc). The training will also include content on confidentiality, and the expectation that they assure the confidentiality of all discussion that takes place on the course. Adolescent co-trainers will be obligated as well to follow the ground rules decided by training participants.

### **Providing feedback to adolescent co-trainers**

You, as the trainer, should make a point to give your adolescent co-trainers feedback after training every day. Consider setting aside 10 minutes after every training day to meet with them. During that meeting ask:

- *What went well?*
- *What would you like to have done differently?*
- *What questions do you have for me?*

During these meetings your role will be to ask questions, encourage your adolescent co-trainers to talk, keep the meeting focused, and end the meeting on time. When providing feedback, make sure you provide specific feedback on something they did or said (for example, “I found it really helpful when you talked about what it was like for you the first time you attended the clinic” or “Thank you so much for assisting the small group work in Exercise 2, I could see that your input really helped them.”).

In your feedback you should also mention any issues that need to be addressed. When providing feedback, consider yourself more of a “coach” or “mentor” rather than a supervisor. For example, if an adolescent co-trainer gave a response that might have indicated a lack of understanding of the technical content, then pull him or her aside during a break or after the training to discuss and to provide the background technical content that he or she may not have. Always give negative feedback on a one-to-one basis.

Whether meeting with an adolescent co-trainer individually or in a group, ensure that for every constructive comment, you give at least 3 positive comments! Remember — this is probably your adolescent trainers’ first job, so they are just starting to learn the skills needed in the workplace.

### **Payment of adolescent co-trainers**

Ideally, adolescent co-trainers should be paid for their work, in line with their experiences and skills. Sometimes this is not always possible and many adolescents will be willing to undertake this work on a voluntary basis. Remember that even volunteers will need to be reimbursed for travel, hotel and other expenses.

## **Climate Setting<sup>5</sup>**

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To create a climate that supports participants, it is important to ensure that participants feel safe, supported and respected. Take the time to carefully plan the first 20 minutes of the training to create a psychologically safe and supportive environment.

Three strategies for reducing early group discomfort and fostering trust include:

- Arranging the seats so that participants can see each other and the trainer.
- Establishing rapport with participants by greeting them warmly and being pleasant and knowledgeable.
- Facilitating the setting of ground rules by participants. Remember that ground rules need to reflect respect and are intended to build a climate of trust. Use “Exercise 2: Setting Ground Rules and Introducing Daily Activities”, in Module 1, to discuss and set ground rules for this training. Ground rules on which the group might agree include starting each day on time, keeping all information shared confidential, that it is

acceptable to disagree with each other as long as it is done constructively and that there are no stupid questions). Trainers should ensure that they also abide by all of the ground rules.

## **Know your Audience**

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One of the most important resources you, as trainer, can have is to know your audience. Knowing something about the individuals who will be participants at the training will help you tailor content and exercises to participant learning needs. You might want to know the following about the people who will attend an upcoming training session:

**Participant demographics** (for example, age, sex, where they work) — This will help with planning logistics (venue and timing of the training) as well as developing role plays and case studies.

**Education** — Knowing the educational background of participants can help you gauge the level of language to use.

**Job/position** — Knowing participants' jobs or positions will help you to relate the training to their work.

**Knowledge, experience and skills in adolescent HIV care and treatment** — Knowing the incoming knowledge, experience and skill level will help determine the level at which the content should be taught, the time and teaching methods needed to teach content, and the best types of exercises or learning methods for the group. Consider inviting participants with more experience to contribute to the discussion, model role plays and — during small group work — pair up with participants who have less experience.

You can get some indication of participant baseline knowledge, experience and skill by finding out where participants work, their job positions, how long they are been in those positions, and whether they currently see adolescent clients. The pre-test will also help determine participant knowledge level.

**Attitudes** — Knowing participant attitudes towards the training can give you a sense of issues that will need to be addressed. Ask what participants are saying about the training. Are they looking forward to it? Or do they see it as a waste of time? What is their attitude towards the topics to be presented?

### **Ways to learn about the audience**

There are many ways to learn about the audience, including the following:

- Ask participants to complete a training registration form that includes questions on current job title, number of years in this position, educational background, number of months/years working in HIV and

in paediatric/adolescent/adult HIV services, any reservations they have about the training and anything else they would like the trainer to know.

- Have participants complete the pre-test.
- During the training, include Exercise 1: Getting to know each other, in Module 1.
- Talk with the participants before the start of the training, during breaks and meals, or at the end of the day.

## **8 Ways to Manage Time**

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1. Know the content to be taught. Well in advance of the training, study the content to ensure you understand it. If you need help, seek support from an expert. Find out how the content can be shortened or lengthened depending on participant learning needs. Consider how the timetable can be adjusted to create time if needed. For example:
  - Shorten breaks or lunch
  - Lengthen the day (for example, start 30 minutes earlier or end 15 minutes later)
  - Shorten or skip presentations or activities in an area that participants know well
2. Practise before the training. Practise exercise introductions, general content and instructions out loud, using material that will be used for the actual presentation.
3. Be flexible, but use and follow the agenda. The agenda will let participants know how long activities are expected to last. Reiterate time expectations during exercises/activities every few minutes.
4. Keep time. Place a clock or watch where you can see it but where it will not distract participants. Use signs (5 minutes, 1 minute and stop) that tell presenters how much time they have left:
5. Keep the training focused on the objectives.
6. Use the “car park” for discussions that take too much time or are related to, but not critical to, the topic under discussion (see box below).

### **Car park**

The “car park” is a sheet of flip chart paper posted on the wall. The purpose is to provide a place to put important, but currently tangential, topics. When the discussion strays too far from the objective, or runs over time, the trainer can record the topic or question on the flip chart. The topic or question will remain in the “car park” until an agreed time to revisit it, for example, at the end of the training, during a break or during an upcoming module (which is relevant to the topic).

## Dealing with difficult participants

**Table 3: Solution for difficult participants**

<b>Problem characteristic</b>	<b>Potential solutions</b>
<b>Noisy audience</b>	<ul style="list-style-type: none"> <li>• Speak more slowly.</li> <li>• Lower the volume of your voice.</li> </ul>
<b>Silence</b>	<ul style="list-style-type: none"> <li>• Ask open-ended questions.</li> <li>• Be patient: after you ask a question wait and give the audience time to answer. Do not be afraid to use silence to encourage participation.</li> <li>• Use prompts.</li> </ul>
<b>Hostile audience</b>	<ul style="list-style-type: none"> <li>• Put participants at ease by acknowledging their concerns.</li> <li>• When the cause of hostility is misinformation or misunderstanding, be willing to listen to concerns and clarify the issues.</li> <li>• Identify the cause for the hostility, find points of agreement, state your position fairly and sincerely, demonstrate the merits of your position.</li> </ul>
<b>The “talker”</b>	<ul style="list-style-type: none"> <li>• Thank the person for her or his comment and ask if others in the audience have input.</li> <li>• Avoid eye contact.</li> <li>• Touch them on arm, shoulder.</li> </ul>
<b>“The class clown,” “know-it-all,” “lots of questions”</b>	<ul style="list-style-type: none"> <li>• Keep them busy.</li> <li>• Turn him/her into an ally or group leader.</li> <li>• Avoid arguing — save the discussion for break time.</li> <li>• Irrelevant questions — agree to discuss the issue later.</li> </ul>
<b>Whisperers</b>	<ul style="list-style-type: none"> <li>• Pause and make eye contact.</li> <li>• Continue presentation and casually move closer to them.</li> </ul>
<b>Hecklers</b>	<ul style="list-style-type: none"> <li>• Stop and acknowledge their comment(s).</li> <li>• Offer to talk with them after the programme.</li> <li>• Invite them to come up front to speak (in a large group setting).</li> <li>• Give the group permission to respond. Let them help you.</li> </ul>

Adapted from: Edelman, L. (2004). An Overview of Adult Learning.

## Communicating Effectively

Being a good trainer requires good communication skills.

Ways to communicate		
Facial expression	Ears	Feet
Voice	Nose	Mind
Eyes	Hands	Heart

**Table 4: Ways to communicate as a trainer**

Use your....	To.....
<b>Facial expression...</b>	<ul style="list-style-type: none"> <li>• Set the tone of the training (friendly and supportive). If your expression is friendly and approachable it will encourage participants to engage throughout the training.</li> <li>• Convey a friendly expression. Smiles are contagious. If you smile, participants tend to smile back. This is one way to create a friendly and supportive environment.</li> <li>• Provide positive reinforcement. By smiling when people respond, they are more likely to respond again.</li> <li>• Show enthusiasm. If you show enthusiasm for the training it encourages participants to be enthusiastic as well.</li> </ul>
<b>Voice...</b>	<p>Communicate content to participants. Your voice sets the tone of the training (friendly and supportive), conveys most of the content, shows enthusiasm, encourages participation, provides positive reinforcement and can be used to help manage the training.</p> <p>Use a trainer's voice</p> <p>Project your voice so everyone can hear you — what you have to say is important and it is critical that everyone hears you.</p> <ul style="list-style-type: none"> <li>• Vary your pitch — so you sound interesting and provide emphasis to the things that are important.</li> <li>• Use a comfortable and varied pace.</li> <li>• Speak at the right technical level.</li> <li>• Use a friendly tone.</li> </ul>
<b>Eyes...</b>	<p>Communicate with participants.</p> <ul style="list-style-type: none"> <li>• Show enthusiasm.</li> <li>• Encourage participation.</li> <li>• Provide positive reinforcement.</li> <li>• Manage the training.</li> </ul>

	<p>Observe.</p> <p>It is important to observe what is happening to determine:</p> <ul style="list-style-type: none"> <li>• Are participants engaged?</li> <li>• Do participants understand?</li> <li>• What is the energy level?</li> <li>• Are there group dynamics?</li> <li>• Who is not participating?</li> </ul>
<b>Ears...</b>	<p>Communicate with participants.</p> <ul style="list-style-type: none"> <li>• Listen to participants. This is a very important skill for a trainer, especially when creating a participatory learning environment.</li> <li>• Listen and wait for participants to finish what they are saying.</li> <li>• Use pauses to allow participants to respond.</li> <li>• Use silence to manage the training.</li> </ul>
	<p>Hear.</p> <ul style="list-style-type: none"> <li>• Do participants understand?</li> <li>• Are there concerns?</li> <li>• What are the needs of participants?</li> </ul>
<b>Nose...</b>	<p>“Sniff” out problems.</p> <ul style="list-style-type: none"> <li>• If there is trouble in the air check it out. For example, if the equipment becomes too hot you may smell it starting to burn.</li> <li>• Pick up on other types of problems, such as issues between participants or people not understanding the content.</li> </ul>
<b>Hands...</b>	<ul style="list-style-type: none"> <li>• Show expression. Be natural about using your hands. They are a great way to show expression and emphasis.</li> <li>• Encourage participation. An open hand is a non-verbal signal to encourage people to comment.</li> <li>• Provide positive reinforcement. Sometimes a pat on the shoulder can be comforting.</li> <li>• Demonstrate procedures. Hands are used to demonstrate procedures and processes.</li> </ul>

<p><b>Feet...</b></p>	<ul style="list-style-type: none"> <li>• Encourage participation. Moving towards a participant when they comment can encourage them to contribute. It makes you more accessible to participants.</li> <li>• Ease nervousness. Walking around can help ease nervousness and make you feel more relaxed in front of participants.</li> <li>• Provide variety. If you walk around, participants are looking in various places — not always at one spot.</li> <li>• Manage the training. Standing in front of a difficult person with your back to them can convey the message that you want to hear from other people. Standing by people who do not respond can encourage them to contribute.</li> </ul> <p>Moving around the room is beneficial to both participants and trainers. Be cautious, moving around is good, but do not move around so much that it is distracting.</p>
<p><b>Mind...</b></p>	<ul style="list-style-type: none"> <li>• Be adaptable and resourceful. If problems arise, adapt to the situation and use your resourcefulness to handle it.</li> <li>• Be creative. Training sessions can be fun or boring. It is up to you to bring it to life. Think of new and participatory ways to teach the content.</li> <li>• Anticipate problems. Think ahead to what problems might occur and determine possible solutions. This is part of having a back-up plan.</li> <li>• Make positive situations out of negative ones. When problems occur, make them learning situations.</li> </ul>
<p><b>Heart...</b></p>	<ul style="list-style-type: none"> <li>• Show respect. Participants come from many backgrounds and it is important as a trainer that you show respect for all individuals. Even if you do not agree with them, you need to respect their point of view. If you set the tone of showing respect to all participants, it will help them show respect for each other.</li> <li>• Recognise that everyone has his or her own style. Not everyone will do things the same way or at the same pace. As a trainer, it is important to show acceptance for different ways of doing things.</li> <li>• Show support when people make mistakes. As adults we all get embarrassed when we make mistakes. By showing support for individuals in these situations, you create a positive and safe learning environment.</li> <li>• Show compassion. We all have problems and difficult situations, so it is important to show compassion for participants.</li> </ul>

# **Trainer Manual Introduction**

## **Section 3: Tips on Training Methods**

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### **Day 1: Participant Registration**

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Set up a registration table at least an hour before the course is scheduled to start. The registration table is where participants will stop before they enter the training room for the first time. This is where they will:

- Register for the training or sign in (if already registered). The sign in sheet may include spaces for the following information: name, job title, place of employment, address of employer, work phone number, cell phone number and e-mail address.
- Collect their Participant Manuals.
- Collect their pens and notebooks (optional).
- Fill in their nametags; encourage trainers and participants to wear their nametags to facilitate learning of names and long-term networking.

Depending on the size of the group, it is probably sufficient if one trainer and one support person staff the registration table. The trainers should be available at this time to not only meet and greet participants but to troubleshoot should there be problems. This will help to ensure a positive first impression and learning environment.

### **Starting Each Day**

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It is recommended that each training day begin with a summary of key points covered the previous day. This can be done in approximately 15 minutes. Strategies for reviewing the previous day's key points include:

- Write key points on the board or flip chart in the morning, before participants arrive.
- Present key points using a large group discussion format, asking the group, for example: "*What were the most important points from yesterday's presentation?*" You, or another trainer, should then add any additional key points that the group may have missed.
- Alternatively, divide participants into small groups (or pairs) and give the groups about 5 minutes to write down the 3 most important points from the previous day's presentations. After the groups reconvene, ask them to summarise their points.

Once the key points have been summarised, ask participants if they have questions about the material covered the previous day.

## **Anonymous Question Bowl, Basket or Envelope**

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Some questions are difficult to ask in a group. One method to encourage participants to ask questions is to set up a question bowl, basket or envelope along with paper and a pen or pencil, somewhere away from the centre of the room. When participants have a question that they do not want to ask in the group setting, they can write it down and place it in the bowl or envelope any time during the day.

Review all questions in the Question Bowl after training ends each day and then provide responses the next morning.

- **Logistical questions:** Respond to all logistical questions (for example, at what time are we breaking for lunch? Can we finish early on Thursday?) as soon as convenient.
- **Technical questions:** Questions on course content can be read aloud to the group. Give the group some time to think about the questions, and then encourage those who know the answers to respond. It is important to address all questions and ensure that participants leave the session knowing the correct answers. If a participant offers an incorrect or misinformed response, provide the correct answer in a tactful way. If there is no clear answer, tell the group that you will find out the answer and get back to them. Take care to ensure the questioner remains anonymous.
- **Personal questions:** Respond to more personal questions as appropriate, for example, by embedding the response into the presentation or a case study, by facilitating discussion on the topic, or by asking someone who has expertise in that area to respond based on their experience. Again, take care to ensure the questioner remains anonymous.

The Anonymous Question Bowl (Basket or Envelope) will be introduced in Module 1, Exercise 2: Setting ground rules and introducing daily activities.

## **Daily Evaluation — How did it Go?**

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At the end of each training day, you should give each participant 2 small sheets of paper:

1. On one of the pieces participants should draw a smiley face (☺) and write one thing that was good about the day.
2. On the other piece participants should draw a sad face (☹) and write one thing they did not like about the day.

Inform participants that you will be collecting their responses, but that they should not record their names on their papers, so that they can feel comfortable responding honestly.

Ask participants to put their completed “How did it Go?” evaluations into the large envelope before they leave the training each day. Review participants’ comments and suggestions at the end of each day and make improvements during following days.

## **Training Evaluation Form**

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On the last day of training, as part of Module 15, you will ask participants to complete a training evaluation form, which appears as “Appendix 15C: Training Evaluation Form” at the end of the module. This evaluation form is an important source of feedback, and provides much information on how the course should be improved in the future to better meet participant training needs. Only distribute course completion certificates to participants after they have handed in the evaluation form!

You will notice that the 2nd part of the evaluation form is a table that lists each of the modules in this training package. The instructions read “How helpful were each of the training modules to you and your work? If you have specific comments, please write them on the next page.” Participants may find it helpful to complete this section on a daily basis, rather than at the end of the training. So, take about 3–4 minutes at the end of each day, and ask them to turn to “Appendix 15C: Training Evaluation Form” so that they can record their feedback on the modules completed that day. They should feel free to add any comments while they are still fresh (rather than waiting until the last day).

### **Reviewing the evaluation forms**

Upon completion of the training, take at least a half hour to read through the Training Evaluation Forms. If you have access to a database into which the evaluation forms can be input, you can get an average score for each of the questions in the first 2 sections. If such a database is not available to you, then tally up the number of participants who rated that question with a “1”, the number who gave it a “2” and so forth. Focus in on the questions where the ratings were relatively low and think through how these areas can be strengthened.

Look at the ratings for each of the modules, for those modules that received a relatively low rating and think through the exercises and other teaching methods. Can you make changes to the exercises to improve the module? What else can be done to better address learning needs? Closely review the last three questions, the open ended questions. Aim to address suggestions offered in response to “How can we improve this training?” — particularly if mentioned by multiple participants. You should feel free to use the aggregate results of the evaluation forms as evidence to advocate for improvements in the training where you need manager approval.

### **Facilitating a Group Discussion**

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Group discussions allow participants to share their experiences and ideas, solve a problem, or apply content information to different situations.

## **STEP 1: Prepare for the group discussion**

As a trainer it is very important to prepare ahead. Being prepared can prevent many problems from occurring, relieve stress and create a successful exercise. Preparation includes:

- Determining what participants will discuss and what they should get out of it (the objectives).
- Preparing any necessary materials or visuals.

## **STEP 2: Introduce the group discussion**

- Provide clear instructions. Where specific instructions are required, provide them verbally.

## **STEP 3: Conduct the discussion**

- Facilitate the discussion
  - You, as the trainer, should talk only about 20% of the time and participants about 80% of the time.
  - Use questions (open-ended, probing and close-ended) to help guide the discussion.
  - Provide positive feedback when participants contribute.
  - Keep the discussion focused on the objectives. If the discussion starts to get off track, remind the group of the objectives and bring them back to topic.
- Manage group dynamics
  - Ensure that one person talks at a time and there is only one conversation at a time.
  - Encourage all participants to contribute.
  - Encourage mutual respect, especially when participants disagree.
  - If participants start to argue, continue to act as trainer, maintain control and do not take sides in subjective discussions. State that we all agree to disagree and that it is important to show respect for different points of view.

## **STEP 4: Summarise and debrief the discussion**

- State the purpose of the discussion.
- Review key points.
- Come to a conclusion about disagreements.
- Clarify questions and concerns.
- Ask participants what they have learnt from the experience.
- Ask participants how they might use what they have learnt.

## **Facilitating a Small Group Exercise**

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A small group exercise is an activity that allows participants to share their experiences and ideas, solve a problem or apply content information to different situations. In these, participants rather than the trainer do most of the talking. In small group exercises, participants from the large group are

divided into small groups. They conduct the exercise task and then report back to the large group. Small groups are an excellent way to get all participants involved. People are often more comfortable and willing to talk in smaller groups.

### **Adolescent co-trainers and small group exercises**

For each exercise, the trainer should think through how to use the adolescent co-trainers. This will depend on the exercise, willingness of the participants to accept adolescent participation, and the skills and preferences of the adolescent co-trainers. For any particular exercise, you may decide that you want each of the adolescent co-trainers to join a small group and participate as members, or you may prefer that they wander from group to group providing guidance and advice as requested. For other exercises, it might be most appropriate if the adolescent co-trainers do not participate. You, as the trainer, will need to make the decision and support the adolescent co-trainers to implement your expectations for that exercise.

#### **STEP 1: Prepare for the small group exercise**

- See “Table 5: Small group exercise preparation checklist” on page 28.

#### **STEP 2: Introduce the small group exercise**

- Provide clear instructions. This is one of the most important steps in any group exercise. Provide instructions verbally and refer participants to the description of the exercise in their Participant Manuals. Describe the following:
  - Purpose.
  - Who will do what.
  - What are the tasks.
  - When are tasks to be completed (state both the number of minutes and the clock time).
  - Where does the exercise take place.
  - How will the exercise be conducted.
  - How groups will be divided.
  - Ask participants what questions they have and provide clarification.

#### **STEP 3: Conduct the small group exercise**

- Circulate among the small groups. Check to see that the groups understand the activities, timeframe and are following the instructions.
- Manage time. Keep participants on task and follow the timeframe allotted for each portion of the exercise. Stay on time! For ideas on how to manage time see “8 Ways to Manage Time” on page 18.
- Present/report back on small group exercise tasks. Bring participants back to the large group to report on their small group work and discuss their findings. Wait to start the small group presentations until

everyone has stopped working and has rejoined the large group. Remind each group how much time they have to present.

#### **STEP 4: Summarise and debrief the small group exercise**

- State the purpose of the exercise.
- Review key points.
- Come to a conclusion about disagreements.
- Clarify questions and concerns.
- Identify common themes that were apparent in the groups' presentations.
- Ask participants what they have learnt from the experience.
- Ask participants how they might use what they have learnt.

**Table 5: Small group exercise preparation checklist**

✓	Step
	<b>Review the small group exercise to ensure you understand it.</b>
	<p><b>Determine how you will divide the large group into small groups.</b></p> <p>There are many different ways to divide participants into groups. It all depends on the exercise. For ideas on how to divide the group, see “Tips on dividing into small groups” on page 29.</p>
	<p><b>Map out the time for each part of the exercise.</b></p> <p>Divide the allotted time amongst each activity within the exercise. Follow suggested time frames where available, or estimate the time based on total exercise time. For example, in general, a group discussion exercise can be divided into the following:</p> <ul style="list-style-type: none"> <li>• Introduce and conduct the exercise.</li> <li>• Conduct a group discussion on the exercise.</li> <li>• Present key points to larger group.</li> <li>• Summarise key points and debrief the exercise.</li> </ul>
	<p><b>Prepare materials.</b></p> <p>Before beginning, collect all materials, equipment and supplies and have them readily available before the small group exercise begins.</p>
	<b>Set up the room, equipment, flip charts, markers and other materials ahead of time.</b>
	<b>Practise giving the instructions and leading the exercise.</b>

## Tips on dividing into small groups

There are many different ways to divide participants into groups. It is helpful to vary how participants are assigned to groups throughout the training so participants are not always in the same group. This helps manage group dynamics and encourages participants to interact with others. Methods for dividing participants into groups often vary according to the exercise but include:

**Counting** — This is good for randomly assigning participants to groups. Have participants count out loud according to the number of groups needed. For example for four groups start at the front of the room and have each participant count off a number. The first person says 1, the second person says 2, the third 3, the fourth 4, the fifth 1, the sixth 2, etc., until all participants are assigned to a group.

**Table** — Have participants work with those sitting at their table or near to them. Two or more tables located close by can work together.

**Job/position** — Sometimes participants represent many different disciplines (nurses, doctors, laboratory personnel). For certain exercises, it can be advantageous to have groups of participants with all the same job title; for other exercises it may be preferable to ensure that each group has a representative from different disciplines.

**Agency or district teams** — Some exercises are designed for agency- or district-specific teams. It can be helpful to have participants work in their teams to encourage team interaction.

**Topic** — When each of the small groups is discussing a different topic, encourage participants to self-select the group they want to work in.

**In pairs** — Have participants work with a neighbour or some other participant of their choice.

**Cards** — Distribute cards with a different word, colour, or symbol for each group to participants, either before the exercise or as they enter the room.

## Facilitating a Role Play

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A role play or drama is a simulation or demonstration during which a real-life situation is presented to the group as a skit by two or more volunteer participants (or the trainers). The role play situation dramatises different functions, characters and perspectives, not only for those playing the roles (the actors), but those watching the role play activity (observers).

## Why use role plays?

- They demonstrate real-life situations and allow participants to react to those situations.
- They also demonstrate
  - Personal interactions
  - Attitudes
  - Processes or procedures
  - Emotions
  - Procedures
  - Behaviours (good, bad, controversial)

## STEP 1: Prepare for the role play

Follow “Table 6: Role play checklist” on page 31.

## STEP 2: Introduce the role play

- Provide clear instructions. Provide instructions verbally and refer participants to the description of the role play in their Participant Manuals.
- Your instructions should describe the following:
  - Purpose of the role play
  - The situation/scenario
  - Who will do what: what the actors will do, who each character is, who will play each character, what will the observers (other participants) do
  - Mention that the actors represent roles that are not necessarily their own attitudes or situations
  - What tasks are to be completed
  - How long the role play will last (state both the number of minutes and clock time)
- Ask actors to speak loud enough for everyone to hear.
- Check for clarification. Ask participants what questions they have.

## STEP 3: Conduct the role play

- **Begin the role play.** Ensure all participants understand the exercise. Explain that the actors are representing roles or perspectives that are not necessarily their own. Encourage the actors to let themselves feel and act like the characters.
- **Facilitate the role play.**
  - Watch to see if the actors are raising issues that are appropriate to the main problem. If they are not, the trainer can discuss issues that ought to have been raised in the role play during the summary by asking, “*What if the actor had done such and such?*”
  - Watch to see if participants are engaged. If they are losing interest, the trainer might consider ending the role play.
  - Keep the role play on time. Give signals to the actors to indicate when they have 5 minutes left, 1 minute left and when to stop.
- **End the role play.** Stop the role play when:
  - The time is up

- The actors have shown the feelings and ideas that are important for the role play
- When others become restless
- If the role play is not working
- **Debrief and de-role the actors.** Thank the actors for their help and good work. Ask the actors:
  - *How do you think it went?*
  - *How did it feel taking on the role?*

De-role (relieve) the actors of their roles — especially for role plays with strong emotional content. This is critical in role plays dealing with HIV. It can be quite emotional to role play someone with HIV or someone counselling a client with HIV. It helps to bring people back into reality after the role play. One possible technique used to de-role is to ask the actors several questions about themselves such as:

- *What is your name?*
- *Where do you work?*

Another way is to remind the actors of their real-life identities: *“Take a deep breath. You are no longer Mary the Teacher; you are back to being Sophia the Nurse from UTH.”*

- **Manage problems. If the role play did not go as planned:**
  - Discuss what went wrong without blaming or singling out participants
  - Make positive situations out of negative ones
  - Turn the problem into a learning situation

#### **STEP 4: Summarise and debrief the role play**

- Ask observers:
  - *What did you observe?*
  - *What went well?*
  - *What did you learn from the role play?*
  - *How might you apply what you learnt to your job?*
- If observers were given a specific task, review it with them
- Address questions and concerns

**Table 6: Role play checklist**

✓	Step
	<b>Review the role play to understand it.</b>
	<b>Determine</b> what the actors and other participants will do throughout the role play.
	<b>Prepare any materials.</b> Before the training, collect all materials, equipment and supplies and have them readily available before the discussion begins.
	<b>Map out the time for each part of the role play.</b> Determine how much time is needed for each part of the role play.

	<p>For example:</p> <ul style="list-style-type: none"> <li>• Select and prepare actors</li> <li>• Introduce role play</li> <li>• Conduct role play</li> <li>• End the role play</li> <li>• Summarise the role play</li> </ul>
	<p><b>Choose and prepare the actors.</b></p> <p>Choose (or ask for volunteers) the actors (sometimes the trainers are the actors). It is helpful to choose the actors ahead of time so they can prepare for their roles. Describe to the actors:</p> <ul style="list-style-type: none"> <li>• The purpose of the role play.</li> <li>• The situation/scenario/problem.</li> <li>• Each role and how each actor should act (what are the characteristics of each actor and how should they respond).</li> <li>• How much time the role play should take and what signals you will give them during the role play to let them know how much time is left.</li> <li>• What the observers will do.</li> </ul> <p>Provide actors with scripts and props. Encourage the actors to let themselves feel and act like the characters. Emphasize that they will need to speak loudly enough for everyone to hear. If possible give them an opportunity to practise ahead of time.</p>
	<p><b>Set up the room, equipment, flip charts, markers and other materials ahead of time.</b></p>
	<p><b>Practise giving the instructions and leading the follow-up discussion.</b></p>

## **Tips for Amending or Replacing Exercises**

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There are many reasons a trainer may wish to adapt an exercise. For example:

- If the trainer has simplified a session to suit the target group, the exercise(s) may also have to be changed.
- The trainer may substitute the exercise in the module with one that is more relevant to the context. Ensure that all the points to be illustrated are included in the replacement content and activities.

If the trainer chooses to adapt, amend or replace an exercise, she or he should ask the following questions:

1. *Is the task in the new exercise clearly defined?*
2. *Is the new exercise consistent with the content of the module?*
3. *Does the new exercise achieve the same objective(s) as the original exercise?*
4. *Does the new exercise fit in the time allotted?*
5. *Does the new exercise contribute to the variety of exercises?*
6. *Does the new exercise make people think?*
7. *What advantages does the replacement exercise have over the original exercise?*
8. *What materials will I need?*
9. *Do I need to create new PowerPoint slides for the exercise?*

## References and Resources

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<sup>2</sup> Vella, Jane K. (1994). *Learning to Listen, Learning to Teach: The Power of Dialogue in Educating Adults*. San Francisco: Josey-Bass, Inc.

<sup>3</sup> California Nurses Association. (1990). *AIDS Train the Facilitator Programme for Health Care Providers*.

<sup>4</sup> Bonner Curriculum. (undated). *Facilitation 202: More Techniques and Strategies*  
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<sup>5</sup> Health and Disability Working Group, BU School of Public Health. (2003). *A Kaleidoscope of Care: Responding to the Challenges of HIV and Substance Use*, 2nd ed.  
<http://www.hdwg.org/resources/curricula/kaleidoscope-care-training-curriculum-module-i-introduction>



# Module 1 Introduction and Course Overview



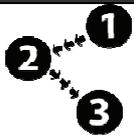
**Total Module Time:** 120 minutes (2 hours)

## Learning Objectives

**After completing this module, participants will:**

- Know more about the trainers and other training participants and have discussed expectations for the training.
- Be able to explain the importance of a training specific to adolescent care and treatment.
- Understand the training objectives and agenda.
- Have set training “ground rules”.
- Have completed the training pre-test.
- Have explored their own values and attitudes around adolescents and adolescent HIV care and treatment.

## Methodologies



- Interactive trainer presentation
- Individual reflection
- Large group discussion
- Large group exercise
- Pre-test

## Materials Needed



- Slide set for Module 1
- Flip chart and markers
- Nametags
- Registration sheet
- Tape or Bostik
- Bowl to be used as Anonymous Question Bowl
- 1 large envelope to collect “How did it Go?” papers
- One copy of the Participant Manual for each participant
- One notebook for each participant
- One pen for each participant

## References and Resources



- None for this module



### Advance Preparation



- Prepare the training room in advance. In order to maximise interaction among participants and trainers, participants should ideally sit in a semi-circle, instead of in rows.
- Make sure you have all of the materials listed in “Materials Needed” on the first page. In particular, make sure there are enough copies of the Participant Manual, so that each participant can have their own, which they will take home after the training.
- Finalise the training agenda using “Appendix 1A: Sample Training Agenda” as a guide; make enough copies of the final agenda so that each participant can have one.
- Prepare a registration sheet in advance and ask participants to sign in as they arrive on the first day of training (see the section entitled “Course Schedule” at the beginning of this manual).
- Invite a guest speaker to open the training (optional).
- Exercise 3 requires advance preparation by the trainer. Please review this exercise ahead of time.

### **Session 1.1: Welcome and Introductory Activity**

<b>Activity/Method</b>	<b>Time</b>
Welcome and registration	5 minutes
Exercise 1: Getting to Know Each Other: Large group discussion and individual reflection	30 minutes
Total Session Time	35 minutes

### **Session 1.2: Training Objectives, Agenda, and Ground Rules**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation and large group discussion	10 minutes
Exercise 2: Setting Ground Rules and Introducing Daily Activities: Large group discussion	20 minutes
Questions and answers	5 minutes
Total Session Time	35 minutes

### **Session 1.3: Training Pre-Test**

<b>Activity/Method</b>	<b>Time</b>
Pre-test	25 minutes
Total Session Time	25 minutes

### **Session 1.4: Values Clarification**

<b>Activity/Method</b>	<b>Time</b>
Exercise 3: Values Clarification: Large group exercise	25 minutes
Total Session Time	25 minutes

## Session 1.1

# Welcome and Introductory Activity



**Total Session Time:** 35 minutes



### Trainer Instructions

Slides 1-4

**Step 1:** Introduce yourself and the other trainers and welcome participants to the training. Officially open the training workshop (or ask an invited guest to do so). If a guest speaker is invited, meet with this person before the training so that you can brief her or him about the workshop, including the goals, objectives and participant expectations.

**Step 2:** If participants did not sign in as they entered the training room, circulate a registration sheet for participants to sign. Encourage everyone, participants and trainers alike, to wear the nametag given to them at registration (see the section entitled “Course Schedule” at the beginning of this manual).

Give each participant a notebook, pen, and a copy of the Participant Manual. Explain that the Participant Manual includes all of the key information that will be discussed in the training, as well as guidance on the training exercises. Participants will be expected to follow along in their manuals and take notes during the training. Encourage participants to use their manuals as reference after the training.

**Step 3:** Review the Module 1 learning objectives, note that the first module objective is the objective for this session.

### Session Objective

**After completing this session, participants will:**

- Know more about the trainers and other training participants and have discussed expectations for the training.

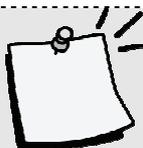


### Trainer Instructions

Slides 5-7

**Step 4:** Facilitate Exercise 1 to start the process of creating an open, comfortable atmosphere and to help participants get to know

one another better.



### Make These Points

- As we will be together for the next 8 days, it makes sense to start the training with an exercise that gives participants an opportunity to get to know each other. The more comfortable participants feel, the more they will get out of this training.

### Exercise 1: Getting to Know Each Other: Large group discussion and individual reflection

<b>Purpose</b>	<ul style="list-style-type: none"><li>• To provide an opportunity to get to know one another a bit better</li><li>• To create a comfortable learning environment</li><li>• To introduce and understand the role of the adolescent co-trainer (optional)</li><li>• To discuss participants' concerns about adolescent HIV care and treatment, expectations for the training, and personal and professional strengths</li></ul>
<b>Duration</b>	30 minutes
<b>Advance Preparation</b>	None
<b>Introduction</b>	This is an activity that will help us get to know one another better. It will also give us a chance to talk about our concerns, expectations for the training, and our strengths.
<b>Activities</b>	<p><b>Introductions</b></p> <ol style="list-style-type: none"><li>1. Ask participants to state their name and position, and to share one memorable experience from their own adolescence (good or bad).</li><li>2. (optional) Introduce the adolescent co-trainer(s) (see "Trainer Tools" section earlier in this manual) that will be joining the group throughout the training. Explain that the adolescent co-trainer(s) brings his or her expertise as an adolescent client living with HIV and enrolled in care and treatment. Participants should consider the adolescent co-trainer(s) as an important resource throughout the training.</li></ol> <p><b>Individual Reflection</b></p> <ol style="list-style-type: none"><li>3. Next, distribute one card or sheet of paper to each participant. Explain that they will not be collected.</li><li>4. Ask participants to spend a few minutes thinking about the following questions, and then to write their</li></ol>

responses on their card or paper.

- **Concerns:** What concerns or worries do you have about providing care to adolescents living with HIV?
- **Expectations:** What do you hope to learn from this training course?
- **Strengths:** What is one personal strength you think helps, or will help you, work effectively with adolescent clients?

5. While participants complete their answers, write the words “Concerns,” “Expectations,” and “Strengths” each on separate pieces of flip chart and tape it to the wall (or use Bostik).

### **Large Group Discussion**

6. Next, lead a group discussion. Begin with “Concerns.” Start the discussion by giving an example of a concern you have had — for example, *“When I first started working with adolescents, I was worried that it would be hard to talk with them about their sexual health.”* Ask for responses and write each on the flip chart. Allow for some discussion while writing down each of the concerns mentioned.
7. Ask participants what they hope to learn — their “Expectations” for the training. Explain that although the training has many objectives, it is important that the facilitators learn what particular issues participants want information about. Write these on the flip chart. Tell the group that you will keep their expectations visible during the entire training and try to ensure they are met when possible.
8. Ask the group for the “Strengths” they each bring to their work with adolescents. Give examples such as “experience” or “sense of humour” to get the discussion started. Discuss participants’ strengths and the role they play in the care they provide to adolescents. Encourage them to value these strengths. Stress that although healthcare workers often do not get enough recognition, the work they do is extremely important.
9. Post the completed “Concerns,” “Expectations,” and “Strengths” flip chart sheets on the wall. The lists will be discussed again on the last day of training, but the trainer should feel free to refer to them, for example, as various “Expectations” are met or as the “Strengths” come up in discussion as a way of resolving an issue.

## Session 1.2      Training Objectives, Agenda, and Ground Rules

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**Total Session Time:**      35 minutes



### **Trainer Instructions** Slides 8-9

**Step 1:**      Review the session objectives with participants.

### **Session Objectives**

#### **After completing this session, participants will:**

- Be able to explain the importance of a training specific to adolescent care and treatment.
- Understand the training objectives and agenda.
- Have set training “ground rules”.



### **Trainer Instructions** Slides 10-17

**Step 2:**      Ask participants why they think a training specific to adolescent HIV care and treatment is important. Ask participants how the needs of adolescents with HIV different from those of adults with HIV.

Review key facts and statistics about adolescents and HIV globally and in Zambia. Ask participants what thoughts they have about these statistics and what the high prevalence of HIV in children and young people might mean for our future as a country. As it is early in the training, participants may not yet feel comfortable sharing their feelings, so do not push for a response to this question if participants are not yet ready to share.

**Step 3:**      Review with participants the learning objectives for this 8-day training.



### **Make These Points**

- Among young women aged 15–24, HIV prevalence is more than twice that of men in this age category (8.9% versus 4.2%).
- Young people are at the centre of the HIV epidemic in Zambia as they are particularly vulnerable to HIV infection for social, political, cultural, biological, and economic reasons.
- Adolescents living with HIV are a diverse group, who face unique health-related, adherence, and psychosocial issues and challenges.
- Programmes and clinics should be youth-friendly and healthcare workers need the knowledge and skills to best attract, retain, and serve adolescents living with HIV with quality services and support.
- This course will provide participants with important information and skills that will help them provide quality HIV care and treatment, as well as adherence and psychosocial support, to adolescents.
- This adolescent training course complements the national paediatric HIV care and treatment training, which most participants should have already attended.

## **Key Facts about Adolescents and HIV**

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### **Globally:**

- In 2007, 40% of new HIV infections in people age 15 and over were among youth 15–24 years of age.
- 5.4 million youth are living with HIV — 61% of whom are in sub-Saharan Africa.
- Due to increased accessibility of ARVs, more children perinatally infected with HIV are living longer and reaching adolescence and adulthood.

### **In Zambia<sup>1, 2</sup>:**

- 120,000 children between the ages of 0–14 years are living with HIV<sup>3</sup>.
- Among young women, HIV prevalence is more than twice that of men of the same age:
  - The HIV prevalence for 15–24 year old males is 4.2%.
  - The HIV prevalence for 15–24 year old females is 8.9%.
- 37% of young men and 34% of young women have comprehensive knowledge of HIV and can correctly identify ways of preventing the sexual transmission of HIV and reject major misconceptions about HIV transmission<sup>4</sup>.
- 48% of young men and 38% of young women reported using a condom the last time they engaged in higher-risk sex.

## **Why a Training on Adolescent HIV Care and Treatment?**

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- Young people are at the centre of the HIV epidemic, as they are particularly vulnerable to HIV infection for social, political, cultural, biological, and economic reasons.<sup>5</sup>
- 74,200 women with HIV give birth each year in Zambia:
  - In 2009, 69% of HIV-infected pregnant women received ARVs to reduce the risk of mother-to-child transmission
- With increased access to paediatric HIV care and treatment, perinatally-infected children are living longer and reaching adolescence and adulthood.
- More young people are being tested for HIV because of increased awareness, reduced stigma, greater access and acceptance of testing, etc. Adolescents who are pregnant are being tested for HIV through PMTCT programmes.
- Youth living with HIV face unique health, adherence, and psychosocial issues and challenges.
- Programmes and clinical services need to be youth-friendly to attract and retain adolescent clients.
- We have successful models of adolescent HIV care and treatment services in Zambia (such as at the University Teaching Hospital in Lusaka), and regionally, that can be scaled-up nationally.
- Healthcare workers need the knowledge and skills to meet the specific needs of adolescent clients.
- Young people are our future!

## **Adolescent HIV Care and Treatment Training Objectives**

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By the end of this training, participants will be able to:

1. Understand how adolescence differs from childhood and adulthood, and how to ensure HIV-related services are tailored to the special needs of adolescents (youth-friendly).
2. Define the package of HIV-related care and treatment for adolescents.
3. Discuss how to establish trust and rapport with adolescent clients using effective counselling skills.
4. Conduct a psychosocial assessment and provide psychosocial support services to adolescent clients.
5. Screen for major symptoms related to persistent mental illness in adolescents.
6. Provide developmentally appropriate disclosure counselling and support to adolescents and, where appropriate, their caregivers or partners.
7. Identify common barriers to adherence and provide age-appropriate support to prepare adolescent clients and caregivers for adherence and to support adherence to care and medicines over time.
8. Support adolescents to live positively and attain key life skills.

9. Conduct sexual risk screening and sexual risk reduction counselling with adolescent clients as a component of sexual health services.
10. List the contraceptive choices available to ALHIV.
11. Provide an overview of PMTCT services for adolescents living with HIV.
12. Actively link adolescents with facility and community-based support services.
13. Prepare and support adolescents through the transition to adult care.
14. Discuss how information from monitoring and evaluation can be used to support programme improvement.
15. Demonstrate core competencies in adolescent HIV care and treatment services in a clinical setting.
16. Develop a site-specific action plan for implementing adolescent HIV care and treatment services.



### **Trainer Instructions**

Slides 18-19

#### **Step 4:**

Review the training syllabus and agenda with the participants. A sample training agenda is included in Appendix A, but this should be adapted to each training session, based on training schedule, participant learning needs, etc.

Take a moment to stress the following points:

- Stress the importance of group interaction and participation.
- Remind participants to bring their Participant Manual each day, and to be prepared to use it throughout the course.
- Emphasize the logistics of the course, such as daily start times, end times, and breaks.



### **Make These Points**

- The training course consists of 15 modules.
- The training includes both classroom and practical sessions.

## **Training Syllabus and Agenda**

The training includes 15 modules, each with its own learning objectives. Each module is divided into a number of sessions.

- Module 1: Introduction and Course Overview
- Module 2: The Nature of Adolescence and Provision of Youth-Friendly Services
- Module 3: Clinical Care for Adolescents Living with HIV
- Module 4: Communicating with and Counselling Adolescents
- Module 5: Providing Psychosocial Support Services for Adolescents
- Module 6: Adolescents, HIV, and Mental Health
- Module 7: Providing Disclosure Counselling and Support

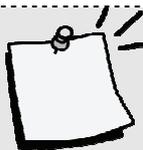
- Module 8: Supporting Adolescents' Retention in, and Adherence to, HIV Care and Treatment
- Module 9: Positive Living for Adolescents
- Module 10: Sexual and Reproductive Health Services for Adolescents
- Module 11: Community Linkages and Adolescent Involvement
- Module 12: Supporting the Transition to Adult Care
- Module 13: Monitoring, Evaluation, Quality Assurance, and Supportive Supervision
- Module 14: Supervised Clinical Practicum
- Module 15: Action Planning, Course Evaluation, and Closure



### Trainer Instructions

Slides 20-21

- Step 5:** Facilitate Exercise 2 to set ground rules for the course and to introduce the daily activities.



### Make These Points

- Ground rules are guidelines for trainers and participants to observe throughout the course. These standards for group interaction will help participants meet their expectations and accomplish course objectives.
- Establishing ground rules offers an opportunity to discuss previous training experiences and to share examples of effective approaches to training.
- All participants should feel comfortable asking any question they have, whether in the large group or anonymously through the Question Bowl.
- All participants should feel comfortable saying things that did and did not go well after each training day. Changes can only be made if you voice your opinions and suggestions!

### Exercise 2: Setting Ground Rules and Introducing Daily Activities: Large group discussion

<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To develop and agree on a set of ground rules that will create an environment that facilitates learning</li> <li>• To introduce the Anonymous Question Bowl as a safe space for asking questions</li> <li>• To introduce the “Morning Rounds” as a way to start off each day of the training on the right foot</li> <li>• To introduce the Daily Evaluation Activity as a way to give feedback to the trainers and to make adjustments DURING the training course.</li> </ul>
<b>Duration</b>	20 minutes

<b>Advance Preparation</b>	<ul style="list-style-type: none"> <li>• Have a large envelope or bowl that can be used as the Anonymous Question Basket</li> <li>• Have 1 large envelope labelled “How did it Go?” for the “How did it Go” daily evaluation</li> </ul>
<b>Introduction</b>	<p>We want to learn about HIV care and treatment for adolescents, but we also want to create a safe space for learning. To do that, we need to agree on some ground rules for the training.</p>
<b>Activities</b>	<p><b>Develop and Agree on the Ground Rules</b></p> <ol style="list-style-type: none"> <li>1. Ask participants what rules will help make them feel comfortable speaking during group discussions.</li> <li>2. If the group is slow to offer suggestions, consider giving the following examples: <ul style="list-style-type: none"> <li>• We will be respectful of others, including in what we say, our posture, and our tone of voice.</li> <li>• We will speak one at a time, and avoid whispering or side conversations.</li> <li>• We will start on time: in the morning and after breaks.</li> </ul> </li> <li>3. As participants contribute ground rules, write the suggestions on flip chart.</li> <li>4. Always be sure to include a rule related to confidentiality (“What is said here, stays here”) and a rule related to turning off mobile phones during the training sessions (participants will have time during breaks and lunch to make/receive calls).</li> <li>5. Post the ground rules on the wall when the group has finished.</li> </ol> <p><b>Introduce the Anonymous Question Bowl</b></p> <ol style="list-style-type: none"> <li>6. Tell participants about the Question Bowl, show them where it is, and invite them to submit questions about any topic addressed in the training at any time.</li> <li>7. Explain that the questions may include concerns they may have about themselves, their families, co-workers, or patients. Tell participants that the Question Bowl will be checked daily, and that all questions will be answered.</li> <li>8. Trainers should review all questions in the Question Bowl after training ends each day and then provide responses the next morning. Technical questions can be read to the group and answered, take care to ensure the questioner remains anonymous. Respond to more personal questions as appropriate, for example, by embedding the response into the presentation or a case study, by facilitating discussion on the topic, or by asking someone who has expertise in that area to respond based on their</li> </ol>

	<p>experience. Again, take care to ensure the questioner remains anonymous.</p> <p>9. Additional information on the anonymous question bowl can be found in the Introduction to the Trainer Manual.</p> <p><b>Introduce the “Morning Rounds”</b></p> <p>10. Tell participants that each morning of the training, we will meet in the classroom for “Morning Rounds.” This will be a time to check in with each other, to recap and answer any questions from the previous day, and to review the agenda for the day.</p> <p>11. We are all under pressures at work and at home, so it is important to start each day of the training as “fresh” as possible. Participants should feel comfortable discussing each morning any distractions or events that are on their minds.</p> <p><b>Introduce the Daily Evaluation</b></p> <p>12. Tell participants that at the end of each training day, the group will debrief using the Daily Evaluation Activity called “How did it Go?”</p> <p>13. At the end of each training day, participants will be asked to anonymously write one good thing about the day and one thing that they would like to improve or that they found challenging about the day.</p> <p>14. Each participant will be given 2 small sheets of paper. On one of the pieces they should draw a smiley face (☺) and write one thing that was good about the day. On the other piece they should draw a sad face (☹) and write one thing they did not like about the day.</p> <p>15. Participants should not put their names on the sheets of paper.</p> <p>16. Participants should put the papers in the labelled “How did it Go?” envelope before they leave the training each day. The trainers will review participants’ comments and suggestions each day and make improvements during subsequent days.</p>
<b>Debriefing</b>	<ul style="list-style-type: none"> <li>• Remind participants that a comfortable and open environment will facilitate the group learning experience.</li> <li>• Encourage participants to speak to one of the trainers if they have any questions or concerns.</li> </ul>



### **Trainer Instructions**

**Step 6:** Allow 5 minutes for questions and answers on this session and be sure to answer any questions about logistics participants may have.

## Session 1.3 Training Pre-Test



**Total Session Time:** 25 minutes



### **Trainer Instructions**

Slides 22-23

**Step 1:** Review the session objective listed below.

### **Session Objective**

**After completing this session, participants will:**

- Have completed the training pre-test.



### **Trainer Instructions**

Slide 24

**Step 2:** Tell participants that they will now be taking the training Pre-test. Inform them that they do not need to write their names on the pre-test. Instead, they should write a number at the top — any number, for example a favourite number or their birth date. But they should remember this number, as they will need to record the exact same number at the top of their post-test. Suggest that they write this number on the inside front cover of their Participant Manuals, so that they will not forget it.

The objective of the pre-test is not to look at individual scores, but rather, to find out what the group as a whole knows about adolescent HIV care and treatment and the group's learning needs. The group's result on the pre-test will guide the amount of time spent on specific modules and highlight learning needs.

This same test will be re-administered at the end of the training, at which point it will be called the post-test.

**Step 3:** Refer participants to "Appendix 1B: Pre-Test". Give participants about 20 minutes to complete the questions. Ask participants to hand their completed pre-tests to a trainer when they have finished. Tell participants that the pre-tests will be scored, and then compared to post-test scores at the end of the training to get a sense of how much participants have learned. The comparison of pre- and post-test scores will provide trainers with information about how well the training went and

identify areas where the training needs to be improved.

**Step 4:** After the pre-test, debrief by asking participants how they felt about the questions. Were they easy or difficult? Inform participants that you will review the test answers after they complete the post-test, which is on the last day of training.

**Step 5:** Once the training has been completed for the day, trainers should

- Score the pre-tests, using “Appendix 1B: Pre-Test” in the Trainer Manual as a guide. Note that Appendix 1B in the Trainer Manual includes the test answers, whereas Appendix 1B in the Participant Manual does not include answers.
- For each of the 25 questions, calculate how many participants got the answer incorrect. Note which questions were most likely to be answered incorrectly and consider if training time is sufficient for these content areas. If not, consider ways to ensure sufficient time is spent on the content areas where participants are weakest (shorten lunch breaks, shorten module time for the content areas that participant have mastered, ask for permission to start the training 15 minutes earlier on one day, etc).



### **Make These Points**

- We are all here to learn and at the end of the training you will all be able to answer all of these questions and many more.

## Session 1.4 Values Clarification



**Total Session Time:** 25 minutes



### Trainer Instructions

Slides 24-25

**Step 1:** Review the session objective listed below.

### Session Objective

**After completing this session, participants will:**

- Have explored their own values and attitudes around adolescents and adolescent HIV care and treatment.



### Trainer Instructions

Slides 26-28

**Step 2:** Facilitate Exercise 3 to help participants explore their own attitudes and values related to adolescent HIV care and treatment. For your information, there is a 2<sup>nd</sup> values clarification exercise in Module 10, which focuses on sexual and reproductive health.

### Exercise 3: Values Clarification: Large group exercise

<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To help participants begin to think about their own values, attitudes, and prejudices, and how these might either positively or negatively impact their work with adolescents.</li> </ul>
<b>Duration</b>	20 minutes
<b>Advance Preparation</b>	<ul style="list-style-type: none"> <li>• Prepare 2 flip chart papers: one that says, “AGREE” and another that says, “DISAGREE.”</li> </ul>
<b>Introduction</b>	This is an activity that will help participants begin to explore their own values, attitudes, and prejudices.
<b>Activities</b>	<ol style="list-style-type: none"> <li>1. Post the prepared flip chart papers that say “AGREE” and “DISAGREE” on opposite sides of the training room. Ideally, they should be posted in an open space where participants are able to move back and forth between signs.</li> <li>2. Ask participants to stand up and move to the open space in the room where the “AGREE” and “DISAGREE” signs are posted. Tell participants that</li> </ol>

	<p>you will read some statements out loud and that, after each statement, they should move to the “AGREE” or the “DISAGREE sign, based on their opinions. If participants are not sure whether they agree or disagree with the statement, they can stand somewhere between the two signs.</p> <p>3. Read out load each of the sentences listed below. Allow participants a few seconds to move to the side of the room that reflects their opinion. Ask a few participants to tell the group why they “AGREE” or “DISAGREE” with the statement. Allow participants to change their answer after these explanations, if desired. Do not worry about explaining the “right” answers, as all of these topics will be discussed later in this training.</p> <p>4. Once you have read all of the statements below, or 20 minutes have passed, ask participants to return to their seats.</p>
<b>Debriefing</b>	<p>Remind participants that members of the multidisciplinary care team should always:</p> <ul style="list-style-type: none"> <li>• Think about the issues related to their own attitudes, values, and prejudices, and how these may affect their ability to provide effective care and treatment services to adolescents</li> <li>• Be sensitive to the culture, values, and attitudes of their clients, even if they are different from their own</li> <li>• Learn what they can about the main culture, values, and attitudes of the clients they work with</li> <li>• Examine their own values and beliefs to avoid prejudice and bias, and to make all people feel comfortable. They should show clients that it is “safe” to talk openly and honestly with them.</li> </ul>

### **Statements for Values Clarification Exercise:**

1. Healthcare workers need to tell adolescents living with HIV how to behave.
2. I think it’s hard to “get through” to adolescents — they just do as they please.
3. Adolescent HIV care and treatment is really not that different than paediatric HIV care and treatment.
4. If an adolescent tests HIV-positive, it is my duty to tell his or her parents.
5. I feel comfortable demonstrating to adolescent clients how to use a condom.
6. It is important to have adolescents living with HIV as part of the multidisciplinary care team at the clinic.

7. Working with adolescents requires different counselling skills than those needed to counsel adults.
8. Adolescents living with HIV should be discouraged from ever having children.
9. Adolescents living with HIV since birth and those who acquire HIV later on often have different psychosocial support issues and needs.
10. Adolescents are so forgetful — they aren't good at adhering to their care and medicines.

## Appendix 1A: Sample Training Agenda

Suggested agenda:

<b>Day 1</b>	
Morning Session	<ul style="list-style-type: none"> <li>• Official Opening</li> <li>• Module 1: Introduction and Course Overview (2 hours)</li> <li>• Module 2: The Nature of Adolescence and Provision of Youth-Friendly Services (3 hours, 5 minutes)</li> </ul>
LUNCH	
Afternoon Session	<ul style="list-style-type: none"> <li>• Module 2 (continued)</li> <li>• Module 3: Clinical Care for Adolescents Living with HIV (3 hours, 25 minutes)</li> <li>• “How did it Go?”</li> </ul>
<b>Day 2</b>	
Morning Session	<ul style="list-style-type: none"> <li>• Recap and “Morning Rounds”</li> <li>• Module 3 (continued)</li> <li>• Module 4: Communicating with and Counselling Adolescents (4 hours, 10 minutes)</li> </ul>
LUNCH	
Afternoon Session	<ul style="list-style-type: none"> <li>• Module 4 (continued)</li> <li>• Module 5: Providing Psychosocial Support Services for Adolescents (3 hours, 35 minutes)</li> <li>• “How did it Go?”</li> </ul>
<b>Day 3</b>	
Morning Session	<ul style="list-style-type: none"> <li>• Recap and “Morning Rounds”</li> <li>• Module 5 (continued)</li> <li>• Module 6: Adolescents, HIV, and Mental Health (2 hours, 55 minutes)</li> </ul>
LUNCH	
Afternoon Session	<ul style="list-style-type: none"> <li>• Module 7: Providing Disclosure Counselling and Support (3 hours, 50 minutes)</li> <li>• “How did it Go?”</li> </ul>
<b>Day 4</b>	
Morning Session	<ul style="list-style-type: none"> <li>• Recap and “Morning Rounds”</li> <li>• Module 8: Supporting Adolescents’ Retention in, and Adherence to, HIV Care and Treatment (4 hours)</li> </ul>
LUNCH	
Afternoon Session	<ul style="list-style-type: none"> <li>• Module 8 (continued)</li> <li>• Module 9: Positive Living for Adolescents (3 hours, 15 minutes)</li> <li>• “How did it Go?”</li> </ul>
<b>Day 5</b>	
Morning Session	<ul style="list-style-type: none"> <li>• Recap and “Morning Rounds”</li> <li>• Module 10: Sexual and Reproductive Health Services for Adolescents (6 hours, 10 minutes)</li> </ul>
LUNCH	
Afternoon Session	<ul style="list-style-type: none"> <li>• Module 10 (continued)</li> <li>• Module 11: Community Linkages and Adolescent Involvement (2 hours, 45 minutes)</li> <li>• “How did it Go?”</li> </ul>
<b>Day 6</b>	
Morning Session	<ul style="list-style-type: none"> <li>• Recap and “Morning Rounds”</li> <li>• Module 12: Supporting the Transition to Adult Care (1 hours, 40 minutes)</li> <li>• Module 13: Monitoring, Evaluation, Quality Assurance, and</li> </ul>

	Supportive Supervision (2 hours, 15 minutes)
<b>LUNCH</b>	
Afternoon Session	<ul style="list-style-type: none"> <li>• Module 14: Supervised Clinical Practicum (2–2.5 days)</li> <li>• “How did it Go?”</li> </ul>
<b>Day 7</b>	
Morning Session	<ul style="list-style-type: none"> <li>• Module 14: Supervised Clinical Practicum (continued)</li> </ul>
<b>LUNCH</b>	
Afternoon Session	<ul style="list-style-type: none"> <li>• Supervised Clinical Practicum (continued)</li> <li>• “How did it Go?”</li> </ul>
<b>Day 8</b>	
Morning Session	<ul style="list-style-type: none"> <li>• Module 14: Supervised Clinical Practicum (continued)</li> </ul>
<b>LUNCH</b>	
Afternoon Session	<ul style="list-style-type: none"> <li>• Module 15: Action Planning, Course Evaluation, and Closure (3 hours)</li> </ul>

## Appendix 1B: Pre-Test

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**NOTE: This version is for trainer only. Correct answers are in bold.**

Participant identification number: \_\_\_\_\_ Score: \_\_\_\_/25

- 1) Which of the following statements are factors in the scale up of adolescent HIV care and treatment services in Zambia? **(select all that apply)**
  - a) Young people are no more vulnerable to HIV than adults.
  - b) Youth living with HIV face unique health, adherence, and psychosocial issues and challenges.**
  - c) Healthcare workers need specific knowledge and skills to meet the needs of adolescent clients.**
  - d) Programmes and clinical services need to be youth-friendly to attract and retain adolescent clients**
  
- 2) Which of the following are characteristics of “youth-friendly” services? **(select all that apply)**
  - a) Special times that allow young people to receive services**
  - b) Services are provided anonymously.
  - c) Healthcare workers are friendly to both male and female clients**
  - d) Clinic services are affordable or available for no fees**
  - e) Healthcare workers create services without the input of adolescents
  
- 3) To be effective, the adolescent package of care must ensure: **(select all that apply)**
  - a) Integration of services**
  - b) That services are age and developmentally appropriate**
  - c) That the needs of both perinatally infected adolescents, as well as those infected later in childhood or adolescence**
  - d) That services are empowering, in other words, they encourage adolescents to take responsibility for their own health**
  - e) That the adolescent client receives care in the paediatric clinic for life
  
- 4) The key clinical components of care for ALHIV differ greatly from care of adults.
  - a) True
  - b) False**
  
- 5) Adolescent clients should be started on ART when their CD4 cell count is:
  - a) Less than 200
  - b) Less than 250
  - c) Less than 300
  - d) Less than 350**
  - e) None of the above

- 6) CD4 cell count should be monitored how frequently?
- a) Every 12 months; but 6 monthly as CD4 count approaches threshold (to initiate ART)
  - b) Every 9 months; but 4 monthly as CD4 count approaches threshold
  - c) Every 6 months; but 3 monthly as CD4 count approaches threshold**
  - d) Every 4 months; but 2 monthly as CD4 count approaches threshold
  - e) Every 2 months; but monthly as CD4 count approaches threshold
- 7) Healthcare workers can use the 5 “A’s” when providing clinical and psychosocial care and support to clients. What are the 5 “A’s”?
- a) Assess, admire, agree, ask, arrange
  - b) Analyze, advise, agree, ask, arrange
  - c) Assess, advise, agree, assist, arrange**
  - d) Assess, advise, assert, ask, arrange
  - e) Awake, advise, agree, ask, arrange
- 8) Counselling includes which of the following? (select all that apply)
- a) Solving another person’s problems
  - b) Helping people to make informed decisions**
  - c) Telling another person what to do
  - d) Respecting everyone’s needs, values, culture, religion, and lifestyle**
  - e) Keeping good records**
- 9) Family-centred care means that healthcare workers can talk openly with caregivers about any information shared between the adolescent and healthcare workers.
- a) True
  - b) False**
- 10) Which of the following are coping strategies that healthcare workers should suggest to clients and caregivers to help them reduce stress and promote psychosocial well-being? (select all that apply)
- a) Talk with a Peer Educator**
  - b) Join a support group**
  - c) Exercise**
  - d) Disclose HIV status to all people in the community
  - e) Change your environment and take a walk**
- 11) Adolescence is a unique stage of life that is characterised by:
- a) Challenging caregivers or elders
  - b) Focus on body image
  - c) Sense of immortality
  - d) Significant physical, emotional, and mental changes
  - e) All of the above**

- 12) Which of the following are signs or symptoms of depression? (**select all that apply**)
- a) **Hopelessness**
  - b) Shaking and sweating
  - c) **Really tired with no energy**
  - d) Heart pounding fast
  - e) **Do not enjoy the things you used to (loss of interest or pleasure)**
  - f) **Sleep too much or not enough**
  - g) **Cannot eat or eat too much**
  - h) Cannot breathe or shortness of breath
- 13) Disclosure is a one-time event, rather than an ongoing process.
- a) True
  - b) **False**
- 14) The process of disclosing HIV status to an adolescent with HIV should include discussion of the following:
- a) The diagnosis, the infection and disease process, and health changes that could occur.
  - b) Strategies to prolong a healthy life (in particular adherence to ART) and responsibilities now and in the future.
  - c) How to cope with the possible negative reactions of others.
  - d) A and C
  - e) **All of the above**
- 15) The Zambia “Adult and Adolescent Antiretroviral Therapy Protocols, 2010” recommends a minimum of 3 adherence preparation visits, as part of a structured treatment preparation plan prior to initiating ART.
- a) **True**
  - b) False
- 16) The only reliable way to assess client adherence is with pill counts.
- a) True
  - b) **False**
- 17) What is positive prevention? (**select all that apply**)
- a) **Partner disclosure and testing**
  - b) Sleeping and resting under an insecticide-treated mosquito net if in a malarial area
  - c) **Sexual risk reduction and sexual health**
  - d) **Prevention and treatment of STIs**
  - e) Bathing regularly
  - f) **PMTCT**
  - g) **Prevention of blood-borne HIV transmission, including transmission through injecting drug use, sharing sharp instruments to cut or pierce the skin.**

- 18) What questions would you ask to screen for alcohol dependency?  
(select all that apply)
- a) **Have you ever felt that you should cut down on your drinking?**
  - b) **Have people annoyed you by criticising your drinking?**
  - c) Have you ever found it difficult to wake up for school or work?
  - d) **Have you ever felt bad or guilty about your drinking?**
  - e) Have you ever experienced rapid heartbeat after drinking?
  - f) **Have you ever had an eye-opener — a drink first thing in the morning to steady your nerves or get rid of a hangover?**
- 19) Which of the following statements is correct?
- a) Healthcare workers need to stress that only heterosexual behaviour is NORMAL
  - b) **Healthcare workers need to stress that homosexual, bisexual, and transsexual/transgendered behaviour is NORMAL**
  - c) Healthcare workers need to stress that homosexual, bisexual, and transsexual/transgendered behaviour is ABNORMAL
  - d) Healthcare workers need to stress that transsexual/transgendered should not be tolerated
- 20) The following sexual activities are considered *high* risk for transmitting HIV: (select all that apply)
- a) **Unprotected (no male or female condom) anal or vaginal intercourse**
  - b) Sharing sexual toys (rubber penis, vibrators) without cleaning them
  - c) Using a male or female latex condom for every act of sexual intercourse (penis in vagina, penis in anus, penis in mouth, etc.)
  - d) Mutual masturbation
  - e) Oral sex without a latex barrier
- 21) The adolescent female genital tract is more biologically susceptible to STIs than that of older women.
- a) **True**
  - b) False
- 22) What advice would you give an ALHIV who wanted to get pregnant?  
(select all that apply)
- a) **It is safest to wait until adulthood to become pregnant**
  - b) Do not eat eggs while pregnant
  - c) **Talk to your provider and ask for his/her advice**
  - d) **Make sure you do not have any opportunistic infections**
  - e) **Make sure you are adhering to your ART regimen**

- 23) Which of the following are good family planning options for ALHIV? **(select all that apply)**
- a) **Condoms**
  - b) **Combined oral contraceptive pills (COCs), progestin-only oral contraceptive pills**
  - c) Spermicides and diaphragms with spermicides
  - d) Male and female sterilisation
  - e) **Hormonal implants**
- 24) In reference to transitioning to adult care, which of the following statements is true? **(select all that apply)**
- a) Clients should be transitioned to adult care by 18 years of age
  - b) **In preparing to transition, the healthcare worker should support the adolescent to develop self-care and self-advocacy skills**
  - c) **In preparation to transition, adolescents should visit and tour the adult clinic**
  - d) Adolescent clients should be encouraged to rely more and more on their caregivers to ensure they adhere to their ART regimen
- 25) Which of the following are examples of indicators? **(select all that apply)**
- a) **Number of adolescents who initiated ART**
  - b) **Number of adolescents currently receiving ART**
  - c) To ensure that 95% of eligible adolescent clients initiate ART.
  - d) To ensure that at least 120 new clients initiate ART in the next 3 months
  - e) To ensure loss to follow up is no more than 5%

## References and Resources

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<sup>1</sup> UNICEF. 2007. Zambia Statistics.

[http://www.unicef.org/infobycountry/zambia\\_statistics.html?q=printme#66](http://www.unicef.org/infobycountry/zambia_statistics.html?q=printme#66)

<sup>2</sup> Zambia Department of Health Services, Central Statistics Office. 2007.

<http://www.measuredhs.com/pubs/pdf/FR211/FR211%5Brevised-05-12-2009%5D.pdf>

<sup>3</sup> UNAIDS. 2009. [Epidemiological Fact Sheet on HIV and AIDS.](#)

<http://www.unaids.org/en/regionscountries/countries/zambia/>

<sup>4</sup> UNAIDS. 2009. [Epidemiological Fact Sheet on HIV and AIDS.](#)

<http://www.unaids.org/en/regionscountries/countries/zambia/>

<sup>5</sup> United Nations Population Fund. Young People: The Greatest Hope for Turning the Tide.

<http://www.unfpa.org/hiv/people.htm>



# Module 2      The Nature of Adolescence and Provision of Youth-Friendly Services



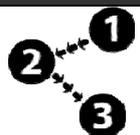
**Total Module Time:**      185 minutes (3 hours, 5 minutes)

### Learning Objectives

**After completing this module, participants will be able to:**

- Define adolescence.
- Identify some of the physical changes that occur during adolescence.
- Define the stages of adolescent development.
- Describe how adolescents living with HIV are different from children and adults living with HIV.
- Discuss the ways in which adolescents are a heterogeneous group.
- Discuss risk-taking as a normal part of adolescence; discuss the consequence of negative risk-taking.
- Discuss some of the vulnerabilities faced by adolescents.
- Describe the characteristics of youth-friendly HIV care and treatment services.

### Methodologies



- Interactive trainer presentation
- Large group discussion
- Brainstorming
- Small group work

### Materials Needed



- Slide set for Module 2
- Flip chart and markers
- Tape or Bostik
- Participants should have a copy of the Participant Manual, which contains background content and information for the exercises.

### References and Resources



- Republic of Zambia, Ministry of Health. 2010. *Guidelines for Antiretroviral Therapy for HIV in Infants and Children in Zambia, Second Edition, 2010.*
- Republic of Zambia, Ministry of Health. *Zambia National Guidelines for Adult HIV Care and Treatment.*



	<ul style="list-style-type: none"><li>• Republic of Zambia, Ministry of Health. 2008. <i>Zambia Paediatric HIV Care Training Course, 2008.</i></li><li>• WHO. 2010 revision. <i>Antiretroviral Therapy for HIV Infection in Adults and Adolescents. Recommendations for a Public Health Approach.</i></li><li>• WHO. 2010. <i>IMAI One-day Orientation on Adolescents Living with HIV.</i></li></ul>
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**Advance Preparation**



- Read through the entire module and ensure that all trainers are prepared and comfortable with the content and methodologies
- Exercise 2 requires advance preparation. Please review ahead of time
- Review the appendices and ensure all trainers are comfortable integrating them into the module.

### **Session 2.1: Stages and Changes of Adolescence**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation and large group discussion	30 minutes
Adolescents, Not Big Children or Little Adults: Small group work and large group discussion	40 minutes
Questions and answers	5 minutes
<b>Total Session Time</b>	<b>75 minutes</b>

### **Session 2.2: Adolescent Vulnerabilities, Risk-Taking Behaviours, and their Consequences**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation and large group discussion	30 minutes
Questions and answers	5 minutes
<b>Total Session Time</b>	<b>35 minutes</b>

### **Session 2.3: Providing Youth-Friendly Services to Adolescents**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation and large group discussion	15 minutes
Exercise 2: Making Services Youth-Friendly: Small group work and large group discussion	50 minutes
Questions and answers	5 minutes
Review of key points	5 minutes
<b>Total Session Time</b>	<b>75 minutes</b>

## Session 2.1      Stages and Changes of Adolescence

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**Total Session Time:** 75 minutes (1 hour, 15 minutes)



### **Trainer Instructions**

Slides 1-5

- Step 1:** Review the Module 2 learning objectives and the session objectives, listed below.
- Step 2:** Ask participants if they have any questions before moving on.

### **Session Objectives**

**After completing this session, participants will be able to:**

- Define adolescence.
- Identify some of the physical changes that occur during adolescence.
- Define the stages of adolescent development.
- Describe how adolescents living with HIV are different from children and adults living with HIV.
- Discuss the ways in which adolescents are a heterogeneous group.



### **Trainer Instructions**

Slides 6-7

- Step 3:** Ask participants to brainstorm what we mean by the terms “adolescence,” “youth,” and “young people.” Record their responses on flip chart; refer to these notes as you present the content on the next four pages.

Start the discussion by explaining the definition of each of these three terms.



### **Make These Points**

- According to the World Health Organization, adolescents are individuals in the 10–19 years age group.
- Youth are individuals in the 15–24 years age group.

- “Young people” refers to both adolescents and youth and includes the 10–24 years age group.
- In this training, we will primarily focus on adolescents, those between the ages of 10–19 years.

## Who Are We Talking About?

Who are we referring to when we talk about “adolescents”? In general, the term “adolescent” refers to people in their second decade of life, that is, those between the ages of 10 and 19 years. Other commonly used terms are “youth” and “young people”, which have slightly different definitions (see Table 2.1), but are sometimes used interchangeably with the term “adolescent”.

**Table 2.1: Key definitions**

Group	Age range (according to WHO)
Adolescents	10–19 years
Youth	15–24 years
Young people	10–24 years



Adolescence has many dimensions: physical, psychological, emotional, and sociological. Adolescence is a PHASE of an individual’s life that is defined differently across cultures and communities.



### Trainer Instructions

Slides 8-14

**Step 4:** Ask participants to think about themselves as an adolescent and to think about the adolescents they know in their life (their own children, the children of family members, adolescent clients, etc.).

Divide two or four sheets of flip chart paper into four columns, with the following labels at the top of each column: “physical”, “sexual”, “psychological”, and “emotional”. Then ask participants to brainstorm what they think are the key physical, sexual, psychological, and emotional changes of adolescence. Record their responses under the appropriate column.

**Step 5:** Lead participants in a discussion of the 3 phases of adolescent development, referring participants to Table 2.2 in the Participant Manual.

Ask if any participants live with or have a close friend or family member that is aged 10–15 years. Ask one of these participants to read the column (Table 2.2) highlighting the changes for that age group. When they have finished, ask participants if these changes sound familiar and which changes they notice the most in 10–15 year olds that they know.

Continue to review Table 2.2 by asking if any participants live with or have a close friend or family member that is aged 14–17 years, have a participant read the column for this age group, etc. Repeat again for 16–19 year olds.



### **Make These Points**

- Adolescents undergo rapid growth and development, resulting in physical changes as well as changes in thinking, social skills, problem solving, and relationships. These changes influence how adolescents interact, behave, and process information.
- Adolescence can be categorised into 3 overlapping developmental stages: early adolescence (10–15 years), middle adolescence (14–17 years), and late adolescence (16–19 years). Although ages have been attached to each of these stages, it is important to understand that changes during this period do not necessarily correspond with precise ages, there is much individual variation.
- The 3 stages of adolescent development correspond with the stages in physical, psychological, social and sexual development in the transition from childhood to adulthood. These stages can provide a basic framework to understand adolescent development.

## **Key Changes During Adolescence**

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There are a number of physical and sexual changes that occur during adolescence.

### **In females:**

- Menarche
- Development of breasts
- Widening of the hips
- Appearance of pubic and underarm hair
- Development of the vulva and pelvis

### **In males:**

- Growth of the penis, scrotum, and testicles
- Night-time ejaculation
- Morning erection
- Development of back muscles
- Appearance of pubic and underarm, chest, and leg hair

The staging system used most frequently to categorise these changes is referred to as "Tanner stages", and is described in "Appendix 2A: Tanner Scale". The first stage in each section represents the pre-pubertal child and the final stage represents the "mature" or adult stage. The Tanner scale is also used to determine maturity when deciding whether an adolescent should receive an adult or paediatric ARV regimen and dosage, as discussed in the next module.

### **In both females and males:**

- Accelerated growth
- Increased perspiration
- Presence of acne
- Face has characteristics of young adult
- Change in tone of voice
- Sexual desire activated
- Initiation of sexual activities

There are also a number of psychological and emotional changes that occur during adolescence<sup>1</sup>:

- Mood swings
- Insecurities, fears, and doubts
- Behavioural expressions of emotion, which may include withdrawal, hostility, impulsiveness, non-cooperation
- Self-centeredness
- Feelings of being misunderstood and/or rejected
- Fluctuating self-esteem
- Interest in physical changes, sex, and sexuality
- Concern about body image
- Concern about sexual identity, decision-making, and reputation
- Need to feel autonomous and independent

## **The Stages of Adolescent Development**

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Adolescence can be categorised into 3 overlapping developmental stages:

- The ages listed are approximate; maturation is more important than specific ages when discussing adolescent development.
- Maturation occurs in fits and starts and is not always coordinated.
- Growth in each of the categories listed in Table 2.2 can occur at different rates. For example, an adolescent girl may look like an adult physically (a characteristic of late adolescence), but not yet capable of abstract thinking (a characteristic of early adolescence). Another adolescent may appear small and stunted, but show advanced intellectual maturity.
- HIV disease impacts maturation in a number of ways (as discussed in the next section).

**Table 2.2: Stages of adolescence**

Category of change	EARLY 10–15 years	MIDDLE 14–17 years	LATE 16–19 years
<b>GROWTH OF BODY</b>	<ul style="list-style-type: none"> <li>• Secondary sexual characteristics appear</li> <li>• Rapid growth reaches a peak</li> </ul>	<ul style="list-style-type: none"> <li>• Secondary sexual characteristics advanced</li> <li>• Growth slows down; reached approximately 95% of adult size</li> </ul>	<ul style="list-style-type: none"> <li>• Physically mature</li> </ul>
<b>COGNITION</b> (ability to get knowledge through different ways of thinking)	<ul style="list-style-type: none"> <li>• Concrete thinking (“here and now”)</li> <li>• Does not understand how a actions affect future</li> </ul>	<ul style="list-style-type: none"> <li>• Thinking can be more abstract (theoretical) but goes back to concrete thinking under stress</li> <li>• Better understands long-term results of own actions</li> </ul>	<ul style="list-style-type: none"> <li>• Abstract thinking now established</li> <li>• Plans for the future</li> <li>• Understands how choices and decisions now have an affect on the future</li> </ul>
<b>PSYCHOLOGICAL AND SOCIAL</b>	<ul style="list-style-type: none"> <li>• Worries about rapid physical growth and body image</li> <li>• Frequent mood changes</li> </ul>	<ul style="list-style-type: none"> <li>• Established body image</li> <li>• Thinks about fantasy or impossible dreams</li> <li>• Feels very powerful</li> <li>• May experiment with sex, drugs, friends, risks</li> </ul>	<ul style="list-style-type: none"> <li>• Plans and follows long-term goals</li> <li>• Established sense of identity (who he or she is)</li> </ul>
<b>FAMILY</b>	<ul style="list-style-type: none"> <li>• Still defining comfort with independence/dependence</li> </ul>	<ul style="list-style-type: none"> <li>• Conflicts with people in authority</li> </ul>	<ul style="list-style-type: none"> <li>• Moving from a child-parent/ guardian relationship to more adult-adult relationships</li> </ul>
<b>PEERS</b>	<ul style="list-style-type: none"> <li>• Important for development</li> <li>• Intense friendships with same sex</li> <li>• Contact with opposite sex in groups</li> </ul>	<ul style="list-style-type: none"> <li>• Strong peer friendships that help to affirm self image</li> <li>• Peer groups define right and wrong</li> </ul>	<ul style="list-style-type: none"> <li>• Decisions/values less influenced by peers in favour of individual friendships</li> <li>• Selection of partner based on individual choice rather than what others think</li> </ul>
<b>SEXUALITY</b>	<ul style="list-style-type: none"> <li>• Self-exploration and evaluation</li> </ul>	<ul style="list-style-type: none"> <li>• Preoccupation with romantic fantasy</li> <li>• Tests how he or she can attract others</li> <li>• Sexual drives emerging</li> </ul>	<ul style="list-style-type: none"> <li>• Forms stable relationships</li> <li>• Mutual and balanced sexual relations</li> <li>• More able to manage close and long-term sexual relationships</li> <li>• Plans for the future</li> </ul>

**Sources:**

WHO. 2003. Orientation Programme on Adolescent Health for Health-care Providers.

WHO. 2010. IMAI One-day Orientation on Adolescents Living with HIV.



### **Trainer Instructions**

Slides 15-20

**Step 6:** Ask participants to give you examples of how HIV can affect normal growth and development during adolescence. Record key points on flip chart, fill in using the content in the next section.

**Step 7:** Ask participants to share ideas on what we mean by the phrase “not big children, not little adults”.

Then ask participants to brainstorm some of the key characteristics that distinguish adolescents from children and adults. Record responses on flip chart and fill in as needed using the content below.

For each of the key characteristic listed, ask participants how this characteristic might have implications on services for adolescents living with HIV. For example, if the characteristic is “influenced by peers,” then the implication might be “peer group can be an important source of support,” etc. If the characteristic is “inquisitive,” then the implications might be “open to new information, takes risks.”



### **Make These Points**

- HIV infection can influence how an adolescent experiences and advances through adolescence.
- There are a number of characteristics that distinguish adolescents from children and from adults. These characteristics influence HIV prevention, care, treatment, and support needs.

## **Effects of HIV Infection on the Changes of Adolescence<sup>2,3</sup>**

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### **Growth:**

- If HIV disease is fairly advanced, an adolescent may experience delays in physical development, including the physical changes of puberty (for example, delayed or irregular menstrual cycles in girls). As a result, ALHIV may appear younger and smaller than other adolescents because they have not begun the physical process of becoming adults.
- ALHIV may be shorter than their peers, either because of stunting early in life or slowed growth throughout childhood and adolescence. This

may lead to a negative sense of self-image and affect how other people view the adolescent — as sick and younger than their actual age.

- ALHIV may experience drug-related side effects including those that change physical appearance, such as lipodystrophy (changes in fat distribution on the body).

### **Cognition:**

- ALHIV experiencing HIV infection of the brain will often have developmental delays and learning problems.

### **Psychological and social:**

- A study of Zambian youth in 2007<sup>4</sup> found that adolescents with HIV were nearly 4 times more likely to experience emotional difficulties than a control group who did not have HIV. The study did not identify the cause of the emotional difficulties, but suggested that it was not necessarily due to health status, but possibly due to the pressures of life and history of loss — less than a fifth of the children surveyed lived with both parents, most were cared for by another family member.
- Interestingly, the same study also found that knowledge of HIV status (that is, adolescents who knew their HIV status) were 2.5 times LESS likely to experience emotional difficulties than the adolescents who did not know their HIV status. This finding contradicts the assumption amongst many caregivers that disclosure is bad for a child's mental health.
- Illness may prevent ALHIV from going to school regularly, making friends, learning sports and hobbies, in short, reducing the number and range of activities that adolescents need to define their identity.
- Managing a chronic disease, including taking multiple medications daily, can have an impact on ALHIV's mental health and sense of fitting in and being like their peers.
- Many ALHIV are not living with one or either birth parent. Although they may be living with extended family, in some cases the adolescent may not feel "attached" or a part of their adopted home, leading to a sense of isolation or that "nobody loves me".

### **Peers:**

- A study found that Zambian adolescents with HIV were 7 times more likely to be experiencing peer problems. The study acknowledged that peer problems may be exacerbated by stigma associated with HIV.
- Adolescents may feel unable to identify with their peers or may feel singled out due to stigma and discrimination.
- ALHIV may have to regularly miss school to attend clinic appointments, which can impact their educational attainment and sense of fitting in with peers.
- If adolescents feel different from their peers, they have a harder time bonding with them. This has an adverse effect on their attachments, making it difficult for them to separate from their parents or caregivers.

## No Longer Children, Not Yet Adults<sup>5</sup>

There are a number of characteristics that distinguish adolescents from both children and adults. However, these are generalisations, some even stereotypes, and are not applicable to every adolescent client. These characteristics may include:

- Energetic, open, spontaneous, or inquisitive
- Unreliable
- Desiring independence
- Influenced by friends
- Less influenced by family
- Looking for role models (often outside of the family)
- Embarrassed to talk to adults about personal issues
- Desire to be different from parents and previous generation

HIV prevention, care, treatment and support services need to be tailored to meet the needs and the characteristics of their adolescent clients. This is referred to as “youth-friendly services” and is discussed further in Session 2.3.



### Trainer Instructions

Slides 21-28

#### Step 8:

Lead participants through Exercise 1, which provides an opportunity to discuss the special needs of adolescent clients, how adolescents differ from paediatric and adult clients, the ways in which adolescents are a heterogeneous group, and the implications of these factors on their care.

When you debrief, draw on the content in the next session “Special Considerations of Adolescent Clients” during the discussion. Once you have completed the exercise, present “Special Considerations of Adolescent Clients”, focusing on the points not covered in the exercise.

### Exercise 1: Adolescents, Not Big Children or Little Adults: Small group work and large group discussion

<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To understand some of the important things healthcare workers should consider about the special needs of adolescent clients</li> <li>• To understand how and why adolescents are a heterogeneous (diverse) group and what implications this has for their care</li> </ul>
<b>Duration</b>	40 minutes
<b>Advance Preparation</b>	<ul style="list-style-type: none"> <li>• None for this exercise</li> </ul>
<b>Introduction</b>	It is often said that adolescents are not “big children or little adults.” It is important for healthcare workers to

	<p>recognise the special needs of adolescents as a group, and how this impacts their care. Adolescents are also a heterogeneous group, with much variation from person-to-person. This exercise will help participants learn more about the special needs of adolescents and the implications for their care.</p>
<p><b>Activities</b></p>	<p><b>Small Group Work</b></p> <ol style="list-style-type: none"> <li>1. Break participants into 3 small groups and ask each to assign a facilitator and a notetaker. Give each group flip chart paper and markers.</li> <li>2. Ask each small group to discuss 1 of the following questions: <ul style="list-style-type: none"> <li>• <i>What are some of the special characteristics of adolescents that healthcare workers need to consider when providing HIV care and treatment?</i></li> <li>• <i>How and why do the needs of adolescent clients differ from those of paediatric and adult clients?</i></li> <li>• <i>We can say that adolescents are a heterogeneous or diverse group. What are some of the differences healthcare workers may see among adolescents? What are the implications for their HIV care?</i></li> </ul> </li> <li>3. Give the small groups 20 minutes to discuss the questions, noting key points on flip chart.</li> </ol> <p><b>Large Group Discussion</b></p> <ol style="list-style-type: none"> <li>4. Ask each small group to briefly (5 minutes or less) report back to the large group, summarising the key points of their discussion. Record key points on flip chart.</li> </ol> <p>Fill in any key information as needed, using the content below titled: “</p> <ol style="list-style-type: none"> <li>5. Special Considerations of Adolescent Clients”.</li> </ol>
<p><b>Debriefing</b></p>	<ul style="list-style-type: none"> <li>• The care, treatment and support provided to an individual adolescent client needs to be tailored to that adolescent’s maturity level, social situation and level of understanding.</li> <li>• ALHIV differ from both children and adults living with HIV because of the rapid changes that occur during this stage of development.</li> <li>• Adolescents are heterogeneous: not only do they differ from each other, but each adolescent will change as he or she matures and develops over time.</li> <li>• Healthcare workers need to understand these differences and consider them when providing care to adolescent clients.</li> </ul>

## **Special Considerations of Adolescent Clients<sup>6</sup>**

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### **Adherence to medication:**

- Although younger adolescents may still rely on a parent or caregiver to remember to take their medicine, older adolescents need to take some — or all — responsibility for taking their medicine every day as directed by the healthcare worker.
- Adolescents often struggle with adherence at different points in their development, as they strive to form their own identity and fit in with peers.

### **Adherence to care:**

- Adolescent clients often have less disciplined/structured lives and may have less stable relationships outside of the family (in comparison to adults), which makes adherence to care and treatment more difficult.
- Adolescent clients are more likely to lack the skills to negotiate health services and understand side effects, treatment options, and regimen requirements than adults.
- Outreach is more difficult for adolescents because they are scattered and it is harder to bring them into care (while children are accessible through their parents and caregivers).
- Adolescents can be lost in the system when in transition from childhood to adolescence, and there is often no follow up or extra support for adolescents when in transition to adult services.

### **Stigma and discrimination:**

- Often, blame is placed on adolescents living with HIV (especially those who acquire HIV behaviourally) because of their “risky behaviour,” resulting in stigma and discrimination.
- The stigma and discrimination associated with HIV prevents many adolescents from disclosing HIV status. This is an issue when the adolescent decides to become involved in a sexual relationship.

### **Counselling adolescents:**

- Adolescents have different cognitive abilities and skills than adults, which require different counselling approaches as well as longer counselling sessions.
- Conflicts between cultural or parental expectations and adolescents’ emerging values can present serious challenges for adolescents.
- Adolescent clients often depend on their parents or caregivers (for example, for money and housing) and therefore cannot always make independent decisions.
- Adolescent clients have a range of future decisions to make, such as whether to have children or get married.
- Adolescents face strong peer pressure and are more dependent on peers for lifestyle guidance.

### **Safer sex:**

- Adolescents may not understand risk-taking behaviour and the importance of risk reduction and are vulnerable to unintended pregnancy and sexually transmitted infections.
- There is a widespread belief that adolescents living with HIV are “not supposed” to be having sex. Since it is taboo, adolescents often hide their sexuality. They also may have limited access to condoms and other contraceptives; even when they do have access to condoms or other contraceptives, they may lack the skills to negotiate their use or to use them correctly.
- For young women with HIV, gender inequality may further reduce their ability to negotiate condom use.

### **How Adolescents Differ from One Another**

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Adolescents are a heterogeneous group. By definition, adolescents range in age from 10 years old to 19. The personality and expectations of a person who is 10 years old is very different that that of a 19 year old, even though both are adolescents. Adolescents differ by stage of development, gender, sexual orientation\*, home and family situation, and educational level; some are rich, others poor; some are from urban areas, others from rural areas. Some adolescents will be in a relationship, some married, and others will have not yet entered a relationship. Some adolescents will know their HIV status, others will not; some will have never experienced stigma or discrimination, while others may face it every day.

Healthcare workers need to assess an adolescent’s care, treatment and support needs and ensure that the plan to meet those needs is tailored to that unique adolescent. Counselling and education, in particular, need to “meet the adolescent where he or she is”.

\* Sexual orientation is further discussed in Module 10.



#### **Trainer Instructions**

**Step 9:** Allow 5 minutes for questions and answers on this session.

## Session 2.2      Adolescent Vulnerabilities, Risk-Taking Behaviours, and their Consequences

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**Total Session Time:**      35 minutes



**Trainer Instructions**  
Slides 29-30

**Step 1:**      Review the session objectives, listed below.

### Session Objectives

**After completing this session, participants will be able to:**

- Discuss risk-taking as a normal part of adolescence; discuss the consequence of negative risk-taking.
- Discuss some of the vulnerabilities faced by adolescents.



**Trainer Instructions**  
Slides 31-35

**Step 2:**      Discuss risk-taking as a normal part of adolescence. Start the discussion by asking participants:

- *What risks did you take when you were an adolescent?*  
Encourage participants to discuss both positive and negative risks.
- *Thinking back on your own risk-taking, why do you think you took these risks?*

Fill in the discussion using the content below. Then discuss some of the consequences of negative risk-taking behaviour, with a focus on consequences for ALHIV.

**Step 3:**      (optional) Ask the adolescent co-trainer to give insights into the positive and negative risk-taking that she or he sees in peers. The adolescent co-trainer should also discuss some of the consequences he or she has seen first-hand (in him/herself or peers).



### **Make These Points**

- Adolescents take risks as a normal part of growing up. Risk-taking is the tool an adolescent uses to define and develop his or her identity, and healthy risk-taking is a valuable experience.
- Risk-taking among adolescents varies with cultural factors, individual personality, needs, social influences and pressures, and available opportunities. Sometimes, negative risk-taking can have lifelong consequences. For ALHIV, this can include poor adherence to medications or discontinuing care, which can lead to drug-resistance, OIs, and other negative health outcomes. ALHIV may also take sexual risks, which can lead to re-infection and/or the further spread of HIV to sexual partners or children.
- When faced with adolescents who are testing their limits, instead of blaming, the healthcare worker must help them avoid facing serious consequences. With support, adolescents can be encouraged to experiment in ways that are healthy and provide valuable life experiences.

## **Risk-Taking as a Normal Part of Growing up**

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Risk-taking, whether healthy or unhealthy, is simply part of an adolescent's struggle to test out an identity by providing self-definition and separation from others, including caregivers.

### **Healthy risk-taking**

- Healthy risk-taking can include participation in sports, the development of artistic and creative abilities, travel, making new friends, constructive contributions to the family or community.

### **Unhealthy risk-taking**

- New social relationships, especially with peers, begin to gain greater importance as family influence decreases.
- Adolescents must attain social autonomy during their second decade of life. This involves moving away from dependence on the family.
- Curiosity, sexual maturity, a natural inclination toward experimentation, and peer pressure can lead to negative, or unhealthy, risk-taking — risk-taking that can be dangerous or appear rebellious — includes drinking, smoking, drug use, reckless driving, unsafe sexual activity, self-mutilation, running away and stealing.
- A sense of omnipotence, feelings of invulnerability, and impulsiveness can lead to a lack of future planning and thereby compromise protective behaviour.
- Lack of knowledge about life's risks. As an example, adolescents may know little about sexually transmitted infections, they may find it

difficult to use condoms consistently and correctly, or lack communication and negotiation skills, making condom use difficult.

- In some cultures, young men are encouraged to take risks as a way of proving their masculinity.

### **Role of the healthcare worker**

- Advise caregivers to seek help if they notice psychological problems such as persistent depression or anxiety which goes beyond more typical adolescent "moodiness"; problems at school; or engaging in illegal activities (mental health issues are discussed further in Modules 5 and 6).
- Healthcare workers can encourage caregivers to:
  - Encourage and help their adolescents find healthy risks, which may prevent unhealthy risk-taking.
  - Share with their children lessons learned from their own histories of risk-taking and experimenting.
  - Help their adolescent to evaluate risks, anticipate the consequences of their choices, and develop strategies for diverting their energy into healthier activities when necessary.

## **Types and Consequences of Negative Risk-Taking Behaviour<sup>7,8</sup>**

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Negative risk taking can include:

- Impulsive decision-making
- Reckless behaviour
- Provoking, arguing, and testing limits with peers and adults

Negative risk taking can result in:

- Poor adherence to HIV-related medication or HIV care and treatment, resulting in a drop in CD4 count, disease progression, opportunistic infections, greater chance of passing HIV to a sexual partner, and drug-resistance.
- Unprotected sex, resulting in unwanted pregnancy, putting partners at risk of HIV infection, unsafe abortion, and a risk of contracting sexually transmitted infections, including re-infection with different strains of HIV.
- Experimentation with substances, such as alcohol and marijuana, resulting in short- and long-term consequences:
  - Substance use and abuse can interfere with judgement and adherence; poor medication adherence will cause a decline in immune-system function.
  - For adolescents on ART, substance use and abuse can adversely interact with HIV medications. For example, alcohol and other psychoactive drugs can magnify the central nervous system side-effects (such as anxiety, nightmares, psychosis, depression) of certain ARVs.

- Like many ARVs, illegal substances are often processed through the liver. Combining the two may lengthen the time that illegal substances stay in the bloodstream, increasing toxicity and the chance of overdose.
- Alcohol reduces inhibitions and affects decision-making. Alcohol also can cloud a person's judgement and give courage to do something he or she would not normally do. A study from Botswana (the study focused on people age 15–49, but findings are most likely applicable to adolescents) found that people under the influence of alcohol were more likely to have unprotected sex, have multiple partners, pay for sex with money or other resources. In addition, intergenerational sex was strongly associated with heavy drinking.
- There is more on adolescents and substance abuse in Module 9.



### **Trainer Instructions**

Slides 36-39

#### **Step 4:**

Ask participants to brainstorm responses to the questions:

- *What do we mean when we say adolescents are vulnerable? Vulnerable to what?*
- *What makes adolescents, and in particular ALHIV, vulnerable to poor health? How about emotionally or economically?*
- *What specifically makes adolescent girls vulnerable? Adolescent boys?*

Encourage participants to think beyond vulnerability to HIV and poor health outcomes. Fill in with the content below, explaining the many levels/types of vulnerabilities that adolescents face. Note that there is more about at-risk adolescents in Module 5.

#### **Step 5:**

(optional) Ask the adolescent co-trainer to comment on the specific things that can make adolescents vulnerable.



### **Make These Points**

- Many adolescents are vulnerable physically, emotionally and socioeconomically. This vulnerability can be amplified for ALHIV due to their health status and their ongoing need for care and treatment.
- Gender issues have a great impact on these vulnerabilities as well, particularly in traditional cultures or families.
- Healthcare workers should remember the reasons that clients may be vulnerable, and how these vulnerabilities relate to risk-taking behaviour and participation in and adherence to their own HIV care and treatment. An understanding of their adolescent clients' lives can

support healthcare workers to assist adolescents to transition safely into adulthood.

## **Physical Vulnerabilities<sup>9</sup>**

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- Young people are more vulnerable to sexually transmitted infections for many reasons (see section entitled “Psychological and Emotional Vulnerabilities” below). Young women (in comparison with adult women) are particularly susceptible, because the cells that normally line the inside of the adolescent cervical canal are more vulnerable to infections than the cells that line the normal cervical canal of the adult female. The prevention or early treatment of sexually transmitted infection in people living with HIV is important to:
  - Avoid increased risk of HIV transmission to partners — many sexually transmitted infections are known to facilitate HIV transmission.
  - Improve survival — sexually transmitted infections can change the natural history of HIV.
- Adolescence is a time of rapid growth and development, creating the need for a nutritious and adequate diet. ALHIV, like all people living with HIV, are particularly vulnerable to nutritional deficiencies due to the increased energy demands that HIV imposes on the body<sup>10</sup>.
- HIV can contribute to compromised physical and psychological development, including stunting and slower than normal growth.

## **Psychological and Emotional Vulnerabilities<sup>11</sup>**

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- Psychological factors that put many adolescents at increased risk of physical harm — which may include anything from an automobile accident to infection with sexually transmitted infections — include a general sense of invulnerability, the desire to try new experiences (including drugs and alcohol), and the willingness to take risks, reckless behaviour, including unsafe sex (for example, changing sexual partners often or having a partner who has multiple partners).
- Mental health problems can increase during adolescence due to the hormonal and other physical changes of puberty, along with changes in adolescents’ social environment. Mental health issues of ALHIV are discussed further in Module 6.
- Adolescents often lack assertiveness and good communication skills, thereby rendering them unable to articulate their needs and withstand pressure or coercion from peers or adults.
- Adolescents may feel pressure to conform to stereotypical gender roles.
- Adolescents are more vulnerable than adults to sexual, physical, and verbal abuse because they are less able to prevent these shows of power.
- Often there are unequal power dynamics between adolescents and adults since adults may still view adolescents as children.

- Adolescents may lack the maturity to make good, rational decisions.

## **Socioeconomic Vulnerabilities<sup>12</sup>**

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- During adolescence, young people's need for money often increases, yet they typically have little access to money or gainful employment. This may lead adolescents to steal or take work in hazardous situations. Girls, in particular, may be lured into transactional sex.
- Poverty and economic hardships can increase health risks, particularly if accompanied by poor sanitation, lack of clean water, and an inability to afford/access healthcare and medications.
- Adolescents are more likely to experiment with drugs and alcohol; disadvantaged adolescents are at greater risk for substance abuse.
- Young women face gender discrimination that affects food allocation, access to health care, adherence to care, the ability to negotiate safer sex, and opportunities for social and economic well-being.
- In many societies, a girl's status is only recognised when she marries and has a child. Some young women marry very young to escape poverty, but as a result may find themselves in another difficult and challenging situation.
- Many young people are at risk for other socioeconomic and political reasons. These especially vulnerable youth include street children, sex workers, child labourers, refugees, young criminals, those orphaned because of AIDS and other circumstances, and other neglected and/or abandoned youth. Most-at-risk adolescents are discussed further in Module 5.



### **Trainer Instructions**

**Step 6:** Allow 5 minutes for questions and answers on this session.

## Session 2.3

# Providing Youth-Friendly Services to Adolescents



**Total Session Time:** 75 minutes (1 hour, 15 minutes)



### Trainer Instructions

Slides 40-41

**Step 1:** Review the session objective, listed below.

### Session Objective

**After completing this session, participants will be able to:**

- Describe the characteristics of youth-friendly HIV care and treatment services.



### Trainer Instructions

Slides 42-45

**Step 2:** Ask participants to brainstorm what we mean by “youth-friendly services.” Record responses on flip chart.

**Step 3:** Next, present to participants the characteristics of youth-friendly services as listed in Table 2.3. Ask participants to react and reflect on these characteristics.

**Step 4:** (optional) Ask the adolescent co-trainer to share some of his or her experiences as a client, highlighting what he or she thinks are the most important characteristics to make adolescents feel welcome and comfortable in the clinical setting.



### Make These Points

- In order to serve adolescent clients with HIV prevention, care, treatment, support and related health services, clinics and programmes must be able to attract, meet the needs of, and retain clients.
- There are a number of key characteristics of youth-friendly services, whether they are for HIV, reproductive health, or other types of care.

## Characteristics of Youth-Friendly Services

**Table 2.3: Characteristics of youth-friendly services**

Healthcare worker characteristics	Health facility characteristics	Programme design characteristics
<ul style="list-style-type: none"> <li>• Specially trained/oriented staff</li> <li>• All staff display respect for youth</li> <li>• Privacy and confidentiality</li> <li>• Enough time for healthcare worker-client interaction</li> </ul>	<ul style="list-style-type: none"> <li>• Separate space for young people</li> <li>• Special times when young people can receive services</li> <li>• Convenient hours</li> <li>• Convenient location</li> <li>• Adequate space and privacy</li> <li>• Comfortable, youth-friendly surroundings</li> <li>• Availability of Peer Educators</li> </ul>	<ul style="list-style-type: none"> <li>• Youth involvement in programme design and monitoring</li> <li>• Drop-in clients welcomed</li> <li>• Short waiting times</li> <li>• Set up to provide chronic disease management, including multiple appointments and medications</li> <li>• Appointment systems in place and tracking systems for clients who miss appointments</li> <li>• Affordable or no fees for services</li> <li>• Publicity, marketing or recruitment materials that inform and reassure youth</li> <li>• Friendly to both male and female clients</li> <li>• Wide range of services available — “one-stop shopping”</li> <li>• Referrals available to clinical and community-based services</li> <li>• Youth-friendly educational materials available to take away</li> <li>• Youth support groups</li> <li>• Peer educators available</li> </ul>

Adapted from: Senderowitz, J., Solter, C., & Hainsworth, G. 2004. *Comprehensive Reproductive Health and Family Planning Training Curriculum. 16: Reproductive Health Services for Adolescents*. Watertown, MA: Pathfinder International.



### Trainer Instructions

Slides 46-47

#### Step 5:

Tell participants that they now know the characteristics of youth-friendly services. The next step is to improve the youth-friendliness of our own HIV clinical programmes and services. Ask participants to brainstorm what steps they might take to make existing clinical services more friendly to ALHIV in their own settings.



### Make These Points

- There are many ways to improve the youth-friendliness of HIV care and treatment services. Additional resources and staff are often not required — and sometimes, even small changes can have a big impact.
- It is important to first assess where we are with adolescent services.

One way of doing this is to conduct a needs assessment of adolescent services currently provided at the health facility.

- Based on findings of the needs assessment, multidisciplinary teams and managers can prioritise key problems and areas for improvement, identify existing human and financial resources, and make a measurable action plan.
- We will talk more about how to improve the youth-friendliness of our services at the end of the training, when participants will create an action plan for their health facility.

## Organising Youth-Friendly Services

There are many things healthcare workers, health facility managers, and youth can do to improve the youth-friendliness of comprehensive HIV care and treatment services. Sometimes, even the smallest adjustments or changes can help, without creating additional workload, or incurring additional costs. A step-by-step guide for developing an action plan to make services more youth-friendly is listed in Table 2.4. This topic will be revisited in Module 15.

**Table 2.4: Making services more youth-friendly**

Step	How
<p>Assess clinic needs: figure out what needs to be done to make services more youth-friendly.</p>	<ul style="list-style-type: none"> <li>• Conduct an assessment using a tool such as that in “Table 2.3: Characteristics of youth-friendly services” and “Appendix 2B: Checklist and Assessment Tool for Youth-Friendly HIV Care and Treatment Services”.</li> <li>• Ask clients what they like about the clinic and what needs improvement. Interview clients who have dropped out of care, ask them why they decided not to attend and what can be done to make the clinic more friendly.</li> <li>• Ask parents what could make services more welcoming for their children.</li> <li>• Ask colleagues what they think needs to change to ensure services are more accessible and meet the needs of young people.</li> <li>• Review national or local reports on the topic or manuals from other clinics or programmes to find out what they have done to attract and retain young people.</li> <li>• Visit a neighbouring clinic that has been very successful in welcoming the youth.</li> </ul>
<p>Design an action plan that will respond to the needs identified in the assessment. This plan should list the</p>	<ul style="list-style-type: none"> <li>• Based on interviews and research during the assessment phase, list the areas that need improvement, and how they can be improved. For example, if several clients mentioned that they are scared of the receptionist because</li> </ul>

<p>most important activities first. For each activity it should include a timeline and list the person responsible.</p>	<p>she's rude, then one of the areas for improvement might read "Ensure that the person who registers clients makes them feel welcome". Then suggest ways to address this need, for example, one-to-one training and support for the current receptionist, relieve the receptionist of other duties so that she can focus solely on welcoming clients, recruit a new receptionist, etc. Be sure to include the date by when this activity will be completed and the person who is going to make it happen. See Module 15 for an example of an action planning template.</p>
<p>Identify existing human and material resources needed to make the plan happen.</p>	<ul style="list-style-type: none"> <li>• Where an activity requires funds, identify the budget from which these funds might be found. Remember, making services youth-friendly does not need to be expensive.</li> </ul>
<p>Present the action plan to stakeholders.</p>	<ul style="list-style-type: none"> <li>• To gain general agreement and support for the action plan, present it first to the manager/supervisor. Work with others in management to ensure the support needed to implement recommended changes. The action plan may need to be revised several times to incorporate their suggestions and ensure their support. Once management has approved the plan, present to healthcare workers and youth that will be involved in the programme.</li> </ul>
<p>Implement, monitor and evaluate.</p>	<ul style="list-style-type: none"> <li>• Start implementing the activities recommended in the action plan. Provide support to the people responsible for each activity. Revisit the action plan monthly at first to see what progress has been made and where adjustments are needed. A year after implementation, evaluate: find out if the action plan has had an affect on the number of clients retained in care by comparing this year's figures with last year's.</li> </ul>

It is important to remember that setting up youth-friendly HIV care and treatment services is the start — but quality, evidence-based HIV care must be provided within the context of youth-friendly services to meet the needs of ALHIV.



### Trainer Instructions

Slide 48

**Step 6:** Lead participants through Exercise 2, which will give them the

chance to learn more about the characteristics of youth-friendly services and how to assess and improve the youth-friendliness of services at their facility.

<b>Exercise 2: Making Services Youth-Friendly: Small group work and large group discussion</b>	
<b>Purpose</b>	<ul style="list-style-type: none"> <li>To learn more about the characteristics of youth-friendly HIV care and treatment services</li> <li>To begin to assess gaps, challenges, and next steps to provide youth-friendly HIV care and treatment services at participants' health facilities</li> </ul>
<b>Duration</b>	50 minutes
<b>Advance Preparation</b>	<ul style="list-style-type: none"> <li>Review "Appendix 2B: Checklist and Assessment Tool for Youth-Friendly HIV Care and Treatment Services" and make additional copies for participants to write on during the training</li> </ul>
<b>Introduction</b>	Now that we know the key first steps to making services more youth-friendly, we are going to talk about HOW to actually do this in our own clinical settings. We will return to this issue at the end of the training, when each participant will contribute to an adolescent HIV care and treatment action plan. But, you should keep the characteristics of youth-friendly services in mind throughout the training, which is why we are discussing them at the start.
<b>Activities</b>	<p><b>Small Group Work</b></p> <ol style="list-style-type: none"> <li>Break participants into 3 (or more) small groups, ensuring that healthcare workers from the same facilities are grouped together.</li> <li>Ask each small group to assign a facilitator and a notetaker. Give each group flip chart and markers.</li> <li>Refer participants to "Appendix 2B: Checklist and Assessment Tool for Youth-Friendly HIV Care and Treatment Services".</li> <li>Ask that the small groups take about 10–15 minutes to read through "Appendix 2B: Checklist and Assessment Tool for Youth-Friendly HIV Care and Treatment Services" and then discuss how this tool might be useful in their clinic setting. Small groups should note key points on flip chart.</li> <li>Ask each small group to select 2 sections of the Tool and to go through each question in that section, reflect on their own clinic, record answers, and then discuss and record comments and recommendations.</li> </ol> <p><b>Report Back and Large Group Discussion</b></p> <ol style="list-style-type: none"> <li>Bring the large group back together and ask each</li> </ol>

	<p>small group to give a brief (2–3 minute) presentation on their small group discussion, including how the Assessment Tool might be useful in their facility and their experiences going through specific sections of the tool.</p> <p>7. Note that we will re-visit this discussion and their partly completed Assessment Tools in Module 15. Recommend that participants keep their notes for that discussion.</p> <p>8. (optional) Ask the adolescent co-trainer to share any thoughts and experiences on the discussion points and on the ways adolescents and adults can work together to make services more youth-friendly.</p> <p>9. Summarise the discussion before moving on.</p>
<b>Debriefing</b>	<p>One of the first steps in making services more friendly to ALHIV is to assess where we are currently and where we need to go from here. One way of doing this is by using an assessment tool, which includes questions on all of the key characteristics of youth-friendly services. We will discuss this more at the end of the training when we develop an action plan for our facilities. Youth-friendly care and treatment services also must include quality, evidence-based care for all clients.</p>



### Trainer Instructions

**Step 7:** Allow 5 minutes for questions and answers on this session.



### Trainer Instructions

Slides 49-51

**Step 8:** Ask participants what they think the key points of the module are. What information will they take away from this module?

**Step 9:** Summarise the key points of the module using participant feedback and the content below.

**Step 10:** Refer participants to “Appendix 2C: Recommended Reading on Adolescent HIV”, where there are recommended readings on adolescent HIV. Encourage participants to read and share these articles.

**Step 11:** Ask if there are any questions or clarifications.



## **Module 2: Key Points**

- Adolescence, the years between the ages of 10 and 19, is characterised by rapid growth and development as well as psychological and emotional changes. Social relationships move from being family-centred to more peer- and community-centred. It is also a time when new skills and knowledge are acquired and new attitudes are formed.
- Young people with HIV can experience adolescence differently; most notably, if HIV disease is advanced the adolescent may have delays in physical development. Social development may be atypical as well, particularly if the adolescent has spent much time ill or if he or she has felt alienated from peers because of HIV-related discrimination or because he or she feels different.
- As part of growing up, adolescents take risks. Risk-taking is the tool an adolescent uses to define and develop his or her identity, and healthy risk-taking is a valuable experience. Sometimes, negative risk-taking can have lifelong consequences. For ALHIV, this can include poor adherence to medications or discontinuing care. ALHIV may also take sexual risks, which can lead to re-infection and/or the further spread of HIV to sexual partners or children.
- Healthcare workers should remember the reasons that clients may be vulnerable, and how these vulnerabilities relate to risk-taking behaviour and participation in and adherence to their own HIV care and treatment. An understanding of their adolescent clients' lives can support healthcare workers to assist adolescents to transition safely into adulthood.
- In order to serve adolescent clients with HIV-related health services, clinics and programmes must be able to attract, meet the needs of, and retain clients.

## Appendix 2A: Tanner Scale

### Boys — development of external genitalia

<b>Stage 1</b>	Pre-pubertal, testes small in size with childlike penis
<b>Stage 2</b>	Testes reddened, thinner and larger (1.6–6cc) with childlike penis
<b>Stage 3</b>	Testes larger (6cc–12cc) and scrotum enlarging; increase in penile length
<b>Stage 4</b>	Testes larger (12cc–20cc) with greater enlargement and darkening of the scrotum; increase in length and circumference of penis
<b>Stage 5</b>	Testes over 20cc with adult scrotum and penis

### Girls — breast development

<b>Stage 1</b>	Pre-pubertal, no breast tissue with flat areola
<b>Stage 2</b>	Breast budding with widening of the areola
<b>Stage 3</b>	Larger and more elevated breast extending beyond the areola
<b>Stage 4</b>	Larger and even more elevated breast; areola and nipple projecting from the breast contours
<b>Stage 5</b>	Mature stage: adult size with nipple projecting above areola

### Boys and girls — pubic hair

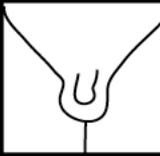
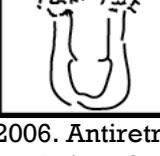
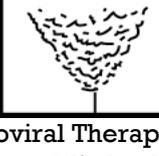
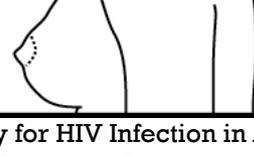
<b>Stage 1</b>	Pre-pubertal, no hair
<b>Stage 2</b>	Small amount of long hair at base of male scrotum or female labia majora
<b>Stage 3</b>	Moderate amount of curly and courser hair extending outwards
<b>Stage 4</b>	Resembles adult hair but does not extend to inner surface of thigh
<b>Stage 5</b>	Adult type and quantity extending to the thigh surface

**Tanner staging system**

**Male genitalia**

**Pubic hair**

**Female breast**

<b>1</b>				
<b>2</b>				
<b>3</b>				
<b>4</b>				
<b>5</b>				

Adapted from: WHO. 2006. Antiretroviral Therapy for HIV Infection in Adults and Adolescents: Recommendations for a public health approach.

## Appendix 2B: Checklist and Assessment Tool for Youth-Friendly HIV Care and Treatment Services

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Facility name: \_\_\_\_\_ Type of facility/clinic: \_\_\_\_\_

	Answer	Comments/Recommendations
<b>Location</b>		
How far is the facility from public transportation?		
How far is the facility from places where adolescents spend their time?		
How far is the facility from local schools?		
<b>Facility hours</b>		
What time is the clinic open?		
Does the clinic have separate hours/days for youth?		
Is there a sign listing services and clinic working hours?		
What times are convenient for adolescents to seek services?		
<b>Facility environment</b>		
Does the facility provide a comfortable setting for young clients?		
Does the facility have separate space to provide services to adolescent clients?		
Does the facility have a separate waiting area for adolescent clients?		
Is there a counselling area that offers both visual and auditory privacy?		
Is there an examination room that provides both visual and auditory privacy?		

Are both young men and young women welcomed and served at the clinic?	+	
<b>Staffing</b>		
Are all healthcare workers trained in paediatric HIV care and treatment?		
Are all healthcare workers trained in adolescent HIV care and treatment?		
Did all staff members (including data clerks, pharmacists, receptionists, etc.) receive orientation about adolescent services?		
Do healthcare workers show respect for adolescent clients during counselling sessions and group sessions?		
Are there job aides available to help healthcare workers in their daily work with adolescents?		
<b>Services provided</b>		
Is one-stop shopping provided to adolescent clients? Describe.		
Are the following services provided to adolescent clients directly (note if through referral):		
• HIV testing and counselling		
• Comprehensive care, including the prevention and treatment of OIs		
• Malaria prophylaxis and tx		
• ARVs/ART		
• Adherence preparation		
• Ongoing adherence assessment & counselling (at each visit)		
• Pregnancy testing, antenatal care and PMTCT		
• Sexual and reproductive health counselling		
• Condoms and lube		
• Contraception (which methods?)		

• STI screening and treatment		
• Positive prevention counselling		
• Psychosocial counselling & support		
• Nutrition counselling		
• Laboratory tests (CD4, other HIV tests)		
• PEP, as per national guidelines		
Are there outreach services, especially to most-at-risk adolescents? Explain.		
Do adolescent request services other than the ones offered? Which ones?		
Is there a formal referral system for services not provided at the clinic?		
Is there a formal referral system for services required by most-at-risk adolescents (sexual abuse counselling and treatment, drug/alcohol rehabilitation, support for youth-heads of household, etc.)? Which ones?		
Is there a tracking and follow-up plan in place for clients who do not return?		
<b>Peer education and counselling</b>		
Is a peer education programme available?		
How many Peer Educators are working at the facility?		
How many hours/days per week do Peer Educators spend at the facility?		
What are the roles and responsibilities of Peer Educators?		
How are the Peer Educators trained?		
Is there a system for supervising and monitoring Peer Educators?		
<b>Educational activities</b>		
Are educational/information materials available?		

Which ones?		
Are there educational posters displayed?		
Are there posters or brochures that describe clients' rights?		
Are there materials for adolescent clients to take home?		
In what languages are materials available?		
Are group education sessions held with younger adolescents? Describe.		
Are group education sessions held with older adolescents? Describe.		
Are group education sessions held with parents/caregivers? Describe.		
Are adolescent support groups held (younger adolescents)? Describe.		
Are adolescent support groups held (older adolescents)? Describe.		
Are there ways for adolescent clients to access information or counselling off-site (hotline, etc.)?		
<b>Youth involvement</b>		
Are adolescents involved in decision-making about how programmes and services are delivered?		
What ways can adolescents give feedback to the clinic?		
How could adolescents be more involved in decision-making at the facility?		
What other roles can adolescents play in clinic operations or guidance?		
<b>Supportive policies</b>		
Do clear, written guidelines or SOPs exist for adolescent services?		
Do written procedures exist for protecting client		

confidentiality?		
Are records stored so that confidentiality is ensured?		
Is parental/guardian/spousal consent ever required? In what cases?		
Is there a minimum age required for adolescents to receive HIV testing?		
Is there a minimum age required for adolescents to receive contraceptives?		
Are there policies or procedures that pose barriers to youth-friendly services?		
<b>Administrative procedures</b>		
Is the registration process private so that others cannot see or hear?		
Can adolescent clients be seen without an appointment?		
How long would an adolescent client normally have to wait?		
What is the average time allotted for client/healthcare worker interaction?		
<b>Publicity/recruitment</b>		
Does the clinic publicize the services available to adolescents and stress confidentiality?		
Are there staff or volunteers who do outreach activities? Describe.		
<b>Fees</b>		
Are adolescents charged for any services? If so, which ones and how much?		
Are any fees affordable to adolescent clients?		
<b>OTHER?</b>		

Adapted from:

Senderowitz, J., Solter, C., & Hainsworth, G. (2002). *Clinic Assessment of Youth Friendly Services: A Tool for Assessing and Improving Reproductive Health Services for Youth*. Watertown, MA: Pathfinder International.

## Appendix 2C: Recommended Reading on Adolescent HIV

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### Adolescent HIV — Cause for Concern in Southern Africa

Glenda E. Gray\*

Perinatal HIV Research Unit, University of the Witwatersrand, Johannesburg, South Africa

In 2006, the Society for Adolescent Medicine issued its second position paper on HIV/AIDS in adolescents [1]. It noted that although great progress had been made in the scientific understanding, diagnosis and treatment of HIV, and the prevention of perinatal transmission, there was a growing HIV crisis in the developing world. At least half of all new infections in the developing world were amongst youth and young adults, and a substantial number of teenagers and young adults were already living with HIV/AIDS [2].

As HIV epidemics mature, increasing numbers of children infected perinatally survive and will present with HIV-related symptoms in older childhood and adolescence. Whilst the epidemiology of sexually acquired HIV infection amongst 15–24 year olds is well described in southern Africa [3–5], few data on the prevalence and disease pattern of perinatally acquired HIV infection in older children and adolescence exist. Recent data from a household survey conducted in South Africa in 2008 estimated the prevalence of HIV in children aged 2–14 years to be 2.5% (95% confidence interval 1.9–3.5) [6]. The survey indicates the relatively high prevalence of HIV in children and adolescents in this region. Most of these infections are acquired early in life and are probably undiagnosed.

#### Linked Research Article

This article discusses the following new study published in *PLoS Medicine*:

Ferrand R, Bandason T, Musvaire, P, Larke N, Nathoo K, et al. (2010) Causes of Acute Hospitalization in Adolescence: Burden and Spectrum of HIV-Related Morbidity in a Country with an Early-Onset and Severe HIV Epidemic. *PLoS Med* 7(2): e1000178. doi:10.1371/journal.pmed.1000178

#### The Survival of Infected Children

Little is also known about the survival of HIV-infected children in Africa beyond 5 years of age. Some studies have estimated that 38% of children will be slow progressors and that the estimated cumulated mortality at 15 years will be 83% [7]. Others estimate a 67% survival at 1 year, 39% at 5 years, and 13% survival at 10 years [8]. Decreased survival of HIV-infected children in Africa to date is attributed to lack of access to antiretroviral therapy (ART), delayed diagnosis, and inadequate management due to lack of expertise and resources.

There are few data on the impact that HIV has on ill-health, morbidity, and mortality in adolescence in southern Africa. A recent study modeled demographic, HIV prevalence, mother-to-child transmission, and child

survival data in South Africa and Zimbabwe [9]. It estimated that without treatment, the HIV prevalence among 10 year olds in South Africa will increase from 2.1% in 2008, to 3.3% in 2020, whereas in Zimbabwe it will decrease from 3.2% in 2008 to 1.6% in 2020. Deaths among untreated slow progressors will increase in South Africa from 7,000 per year in 2008 to 23,000 per year in 2030, and in Zimbabwe deaths will peak in 2014 at 9,700 per year, from 8,000 per year in 2008. The toll of adolescent HIV on other health outcomes such as hospital admissions in these settings has yet to be quantified.

### **A New Study on Hospitalizations**

In this issue of *Plos Medicine*, Ferrand and colleagues present data on the causes of acute hospitalization in adolescence in Zimbabwe [10]. HIV has become the single most common cause of acute admission and in-hospital death amongst adolescents in Harare. Almost half of all adolescents hospitalized were found to be HIV infected, and most of them were severely immunosuppressed, with the major route of transmission being attributed to perinatal transmission. Those admitted were more likely to be stunted, have pubertal delay, be a maternal orphan, or have an HIV-infected mother as compared to non-HIV admissions. Unlike their HIV-negative counterparts, who were largely admitted for trauma or an acute exacerbation of a chronic medical condition, HIV-infected adolescents were more likely to be admitted for an infection with tuberculosis, pneumonia, cryptococcosis, and septicemia. HIV-infected adolescents were also almost four times more likely to die. The risk of in-hospital death was increased in those HIV-infected adolescents who had underlying chronic complications.

These high rates of in-hospital mortality are also seen in other parts of the region. A study conducted in Zambia amongst HIV-antibody positive children aged 1–14 years found that a single hospitalization for a severe bacterial infection increased the risk of death by 42%, and a further hospitalization doubled this risk again [11]. Interventions to decrease HIV-related deaths that occur in hospitals require urgent investigation.

### **Diagnosis, Clinical Manifestations, and Disease Outcome**

Older children and adolescents are diagnosed late in Africa despite most guardians suspecting their children of being HIV infected before diagnosis [12]. The median age of diagnosis in some studies has been found to be between 11–12 years of age [10,12], with a delay of 3.5 years (interquartile range, 1–6 years) between the first serious illness and diagnosis of HIV infection. In addition, when these adolescents are diagnosed, they are already below average for height and weight, have moderate to severe immunodeficiency, and have had recurrent infections as well as tuberculosis.

Most of the hospital admissions for HIV-infected adolescents in Harare in Ferrand et al.'s study were for infectious diseases [10]. It is unclear whether any data were collected on any underlying depression or other

concomitant mental health diagnoses. Few data from southern Africa are available on the psychological manifestations, depressive symptoms, and psychiatric admissions for children and adolescents infected with HIV.

In contrast, studies from the developed world show high rates of admissions for psychiatric reasons amongst HIV-infected children and adolescents. In the United States, the PACTG 219C study — a prospective cohort study designed to examine long-term outcomes among HIV-infected children and HIV-exposed uninfected infants — found the incidence of psychiatric admissions to be 6.17 cases per 1,000 person-years of follow up, which was significantly higher than that reported in the general population (1.70 cases per 1,000 person-years) [13]. In this study, the most common reasons for psychiatric hospitalization for HIV-infected children were for depression or behavioural disorders. The median age for first psychiatric admission was 11 years (range 4–17 years). Knowledge of HIV status increased the risk of hospital admissions 6-fold, and having experienced a significant life event increased the risk of hospitalization 3-fold. Almost half of the admitted children required multiple psychiatric admissions.

A previous study conducted amongst HIV-infected adolescents in Harare shows the tremendous burden HIV has on the family [12]. More than half of the adolescents participating in the study had lost both parents, and chronic ill health was reported in 44% of the surviving parents. Almost half of the adolescents were caring for sick parents, guardians, and/or siblings. The impact of death and chronic ill-health of a caregiver/and or siblings on the mental health of HIV-infected adolescents in southern Africa requires further description.

### **Response to ART**

Access to ART will improve health outcomes and long-term survival of any child that is infected early on in life, irrespective of setting. In the developed world, the long-term effects of protease inhibitor-based combination therapy have shown greater improvements in CD4% in younger children as compared to older children. These findings may reflect greater thymic productivity in pre-adolescent children than in adolescents and adults [14] or other factors such as poorer treatment adherence in older children.

Kekitiinwa and colleagues examined the impact of ART across different geographical settings [15]. They looked at data describing HIV and early growth responses to ART across childhood, and compared initial responses to ART in the United Kingdom/Ireland and Uganda. They found that although early mortality after ART initiation was 3-fold higher in Uganda as compared to the United Kingdom/Ireland, older children and adolescents in Uganda had a superior virological response to ART compared with those from the United Kingdom/Ireland [15]. This difference was largely attributed to successful adolescent support programs at the Mulago Hospital in Kampala.

Additional data from Uganda, assessing the impact of ART on growth and sexual maturation in HIV-infected adolescents, showed appropriate virological and immunological responses to ART, as well as improvements in growth and to a much lesser extent, sexual maturation [16]. In a cohort of 118 perinatally infected, treatment naïve 10–19 year olds, the effect of antiretroviral was evaluated for a period of 12 months. At enrolment, the median CD4 count was 124, which had increased to 304 by 6 months, and to 370 by 12 months of treatment. ART was virologically suppressive in 79% of adolescents at 6 months, and by 89% at 12 months.

### **Disclosing HIV Diagnosis to Adolescents**

Disclosure issues abound both in the developed and developing world. However, studies suggest that there are medical benefits to disclosure of HIV infection status to children and adolescents. Children and adolescents who know their HIV status appear more likely to accept medical care and have a higher self-esteem as compared to youth that are unaware of their status [17,18]. Nondisclosure can be associated with anxiety and depression, in addition to being excluded from social support. Reluctance of parents and caregivers to disclose the HIV status to a child or an adolescent is usually based on the fear of discrimination and stigma, toward both the adolescent and the family as a whole [19,20].

The American Academy of Pediatrics strongly recommends the disclosure of HIV status to adolescents [21], so that they are fully informed about all aspects of their health, including their sexual behaviour. Ferrand and colleagues document a high rate of disclosure amongst HIV-infected adolescents in their study [10]. Nevertheless, they strongly recommend that health professionals include adolescents in routine provider-initiated testing and counselling, and assist guardians with disclosure as a way to improve early diagnosis and adherence to subsequent ART.

### **Sexual Activity**

Adolescents with moderate or severe immunosuppression are less likely to have adrenarche as compared to HIV-uninfected children of their own age [22]. However, the median age of sexual debut of adolescents who acquired their infection perinatally in southern Africa is unknown. In a study conducted in the US, amongst 40 HIV-positive adolescents/young adults, it was found that 28% of youth (mean age of 16.6 years), reported being sexually active [23]. When re-interviewed about 2 years later, 41% (mean age 18.3 years), were sexually active. Other studies examining sexual behaviour of adolescents infected with HIV as infants report sexually activity ranging from 18% (mean age of 15.5 years) [24], to 59% (mean age 18.5 years) in HIV-infected adolescents with hemophilia who ever reported prior sexual intercourse [25].

Of concern in these studies is that although self-efficacy around condom use was deemed to be high, it was not 100% guaranteed [23]. In various studies, between 63% to 80% of perinatally infected adolescents [24,25]

reported using condoms. HIV knowledge of sexual transmission has been found to be low [23], and these data highlight the need to provide risk-reduction counselling to adolescents who acquire HIV early in life.

### **Conclusion**

There is a substantial burden of HIV infection in adolescents in southern Africa who acquired HIV perinatally. It is evident that they contribute substantially to hospital admissions and in-hospital deaths. There is an urgent need for services that will be able to provide accessible and appropriate HIV testing, counselling, and support, as well as facilitate access to ART and appropriate sexual risk-reduction interventions. The adolescents admitted to hospitals in Harare could have benefited from early diagnosis and concomitant initiation of ART, and this absence of treatment should not continue to be the plight of similar adolescents in our region.

### **Author Contributions**

ICMJE criteria for authorship read and met: GEG. Wrote the first draft of the paper: GEG.

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**Competing Interests:** The author declares that she was on the Tibotec Preventing Mother to Child Transmission (PMTCT) advisory board in 2009, for which she was paid, but PMTCT and specific antiretroviral drugs are not discussed in this article. Dr. Gray reports also receiving grant support from GlaxoSmithKline for investigating the prevalence of 3TC resistance in the PETRA and being on an expert panel on HIV for Nestlé Nutrition Institute Africa that assessed interventions to prevent postnatal transmission of HIV.

**Abbreviations:** ART, antiretroviral therapy

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**Provenance:** Commissioned; not externally peer reviewed

### **Box 1. Five Key Papers in the Field of Adolescent HIV**

**Ferrand RA, Banson T, Musvaire P, Larke N, Nathoo K, et al., 2010 [10].** This paper demonstrates the burden of HIV infection in adolescents who acquired HIV infection in early life and how it contributes significantly to hospital admissions and in-hospital mortality. The article also highlights the need for early diagnosis, which will enable HIV-infected adolescents to benefit from earlier access to treatment and care.

**Shisana O, Rehle T, Simbayi LC, Zuma K, Jooste S, et al., 2009 [6].** This report on a national household survey conducted in South Africa shows the prevalence and incidence

of HIV by age, gender, province, and geographic locality. The report also assesses risk behaviour, such as condom use, multiple concurrent partners, and sexual debut over time.

**Ferrand RA, Corbett EL, Wood R, Hargrove J, Ndhlovu CE, et al., 2009 [9].** This paper models the time course and magnitude of the AIDS epidemic among older children and adolescents in Southern Africa. These data are important for health policy makers and economists who need to evaluate the impact that the HIV epidemic has on health resources in Southern Africa.

**Walker AS, Mulenga V, Sinyinza F, Lishimpi K, Nunn A, et al., 2006 [11].** This study evaluates the determinants of survival of HIV-infected children without ART in Zambia. Data from this study demonstrates that malnutrition and hospitalizations for respiratory or bacterial infections predict mortality independent of immunosuppression.

**Kekitiinwa A, Lee KJ, Walker AS, Maganda A, Doerholt K, et al., 2008 [15].** Few studies have directly compared responses to ART between children living in resource-rich and resource-poor settings. This study showed that irrespective of settings, overall immunological and virological responses to ART were similar.

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## Module 3      Clinical Care for Adolescents Living with HIV



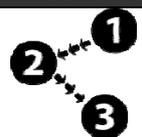
**Total Module Time:**      205 minutes (3 hours, 25 minutes)

### Learning Objectives

**After completing this module, participants will be able to:**

- Discuss the needs of adolescents who acquired HIV perinatally versus those of adolescents who acquired HIV during childhood or young adulthood.
- Discuss the importance of comprehensive care for ALHIV.
- Define the package of HIV-related care and treatment for adolescents.

### Methodologies



- Interactive trainer presentation
- Large group discussion
- Small group work
- Case studies

### Materials Needed



- Slide set for Module 3
- Flip chart and markers
- Tape or Bostik
- Participants should have their Participant Manuals. The Participant Manual contains background technical content and information for the exercises

### References and Resources



- Republic of Zambia, Ministry of Health. *Guidelines for Antiretroviral Therapy for HIV in Infants and Children in Zambia*, Second Edition, 2010.
- Government of the Republic of Zambia, Ministry of Health. *Adult and Adolescent Antiretroviral Therapy Protocols, 2010*.
- Republic of Zambia, Ministry of Health. 2008. *Zambia Paediatric HIV Care Training Course*.
- WHO. 2010. *Antiretroviral Therapy for HIV Infection in Adults and Adolescents. Recommendations for a Public Health Approach, 2010 revision*.
- WHO. 2010. *IMAI One-day orientation on Adolescents Living with HIV, Facilitator Guide*, Geneva, WHO Press.



### Advance Preparation



- Read through the entire module and ensure that all trainers are prepared and comfortable with the content and methodologies.
- Review the “Guidelines for Antiretroviral Therapy for HIV in Infants and Children in Zambia, Second Edition, 2010”, in particular Section 14 “Considerations for ART in Adolescents”.
- Exercise 1 requires advance preparation. Please review ahead of time.

### **Session 3.1: Adolescent HIV Transmission — Modes and Implications for Care and Treatment**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation and large group discussion	25 minutes
Questions and answers	5 minutes
<b>Total Session Time</b>	<b>30 minutes</b>

### **Session 3.2: The Package of Adolescent HIV Care and Treatment Services**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation and large group discussion	100 minutes
Exercise 1: The Adolescent Package of Care: Case studies in small groups and large group discussion	60 minutes
Questions and answers	5 minutes
Review of key points	10 minutes
<b>Total Session Time</b>	<b>175 minutes</b>

## Session 3.1      Adolescent HIV Transmission — Modes and Implications for Care and Treatment

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**Total Session Time:**      30 minutes



### **Trainer Instructions**

Slides 1-4

- Step 1:**      Begin by reviewing the Module 3 learning objectives and the session objective, listed below.
- Step 2:**      Ask participants if they have any questions before moving on.

### **Session Objective**

**After completing this session, participants will be able to:**

- Discuss the needs of adolescents who acquired HIV perinatally versus those of adolescents who acquired HIV during childhood or young adulthood.



### **Trainer Instructions**

Slides 5-16

- Step 3:**      Ask participants:
- *How many adolescents living with HIV are you currently caring for in your clinical setting?*
  - *How many of the adolescents who receive care in your clinic acquired HIV perinatally versus behaviourally (that is, during childhood or adolescence)?*

- Step 4:**      Ask participants:
- *What some of the similarities or differences they have seen between adolescents who were perinatally infected versus those who were behaviourally infected?*

Record responses on flip chart and fill in, as needed, using the content below.

- Step 5:**      (optional) Ask the adolescent co-trainer to share his or her experiences and thoughts about the needs of perinatally infected versus behaviourally infected adolescents.



### **Make These Points**

- There are 2 specific groups of ALHIV (defined by the mode of HIV transmission), whose needs may differ significantly — adolescents who acquired HIV perinatally, and those that acquired HIV later in childhood or adolescence.
- The way an adolescent acquired HIV can influence when and how he or she comes into contact with the health system and their clinical and psychosocial needs.

## **HIV Transmission in Adolescents**

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It is important for healthcare workers to be aware that there are 2 specific groups of ALHIV they will likely serve at the clinic.

### **Adolescents who acquired HIV perinatally**

- This group of adolescents acquired HIV via MTCT — during pregnancy, labour, delivery, or through breastfeeding.
- As paediatric HIV treatment programmes have become more available and accessed, there will be more and more HIV-infected children who survive into adolescence.
- Adolescents in this group may have been enrolled in HIV care since infancy. Others may have been identified later in life during an acute illness or testing campaign.
- Several recent studies suggest that there are significant numbers of perinatally infected adolescents who have been “missed” by the healthcare system, despite being symptomatic.
- Adolescents in this group may have initiated ART in infancy and have taken various ART regimens by the time they reach adolescence. Others may still be taking the initial regimen they started during early childhood.
- Perinatally infected adolescents may or may not have been fully disclosed to (depending on their age and their caregivers). Unlike adolescents who acquire HIV during adolescence, usually at least one caregiver of a perinatally infected adolescent knows about the adolescent’s HIV status.

### **Challenges faced by adolescents who acquired HIV perinatally**

Challenges often relate to disclosure of HIV status to the child (the process of disclosure should, ideally, start at an early age and continue as the child grows and develops), mother’s acceptance of her HIV status (including her commitment to “positive living,” that is enrolment in, and adherence to, lifelong care and treatment), disclosure of the child’s HIV status to family members, acceptance of the child’s HIV status (and mother’s) by family members, amongst other factors. Challenges can include:

- The demands of caring for a child with chronic HIV infection — juggling multiple appointments, tests, and medications.
- Developmental delays in the child.
- Complexity of adhering to HIV-related medications and care, which can be particularly difficult if the adolescent does not know his or her diagnosis. Children of parents who do not adhere to their own regimens will have more barriers to good adherence as they are unlikely to get the support they need.
- The complexity of living in a home affected by HIV — particularly if the parents are unemployed, unwell, or dead; or if the child was adopted and this has not yet been disclosed to the child.

### **Adolescents who acquired HIV during childhood or adolescence**

- This group of adolescents likely acquired HIV through sexual intercourse, or less frequently through a blood transfusion or sharing cutting/piercing instruments, or through injecting drug use.
- It is important to recognise that some adolescents in this group will have acquired HIV through child sexual abuse, including rape.
- Adolescents in this group may have only recently learned their HIV status, and generally have not had long contact with the health system. Adolescents in this group are often identified via HIV testing programmes (VCT, PITC, PMTCT, etc.).
- Many adolescents who acquire HIV during adolescence fall into WHO clinical stage 1 or 2 and may not yet feel unwell or need ART. But, it is important that adolescents not eligible for ART receive ongoing care, support, and monitoring for ART eligibility.

### **Challenges faced by adolescents who acquired HIV during childhood or adolescence**

Challenges often relate to acceptance of HIV status; retention of adolescents in care, especially if they are not eligible for ART; disclosure to family, partner, and peers; adherence; and positive living and positive prevention.

There are a number of differences between these 2 groups of adolescents, as summarised in Table 3.1. Keep in mind that these are **generalisations** and may not apply to all adolescents — each person is unique.

**Table 3.1: Differences and similarities between ALHIV based on transmission period**

DIFFERENCES (AND SIMILARITIES) RELATED TO:	PERIOD WHEN HIV WAS ACQUIRED	
	PERINATAL (dependant on current age and stage of development)	ADOLESCENCE
<b>AGE AT PRESENTATION</b>	<ul style="list-style-type: none"> <li>• Younger: 10–19 years</li> </ul>	<ul style="list-style-type: none"> <li>• Older: 15–19 years</li> </ul>
<b>PHYSICAL DEVELOPMENT</b>	<ul style="list-style-type: none"> <li>• Delayed: short stature</li> </ul>	<ul style="list-style-type: none"> <li>• Normal physical development</li> </ul>
<b>SEXUAL &amp; REPRODUCTIVE HEALTH</b>	<p><b>Differences:</b></p> <ul style="list-style-type: none"> <li>• Not yet sexually active (or if older, may be thinking about sex or have already had sexual debut)</li> </ul> <p><b>Similarities:</b></p> <ul style="list-style-type: none"> <li>• May need SRH services, including safer sex education and support</li> <li>• Wants children</li> </ul>	<p><b>Differences:</b></p> <ul style="list-style-type: none"> <li>• Probably sexually active</li> <li>• May have been sexually abused</li> </ul> <p><b>Similarities:</b></p> <ul style="list-style-type: none"> <li>• Need SRH services, including safer sex education and support</li> <li>• Wants children</li> </ul>
<b>RELATIONSHIPS/MARRIED</b>	<ul style="list-style-type: none"> <li>• No/maybe</li> <li>• Want intimate relationship</li> </ul>	<ul style="list-style-type: none"> <li>• Probably in a sexual relationship(s)</li> <li>• May want marriage</li> </ul>
<b>DISCLOSURE</b>	<p><b>Differences:</b></p> <ul style="list-style-type: none"> <li>• To adolescent, if he or she does not know status</li> <li>• Primary caregiver knows adolescent’s HIV status</li> </ul> <p><b>Similarities:</b></p> <ul style="list-style-type: none"> <li>• Disclosure to family and peers</li> </ul>	<p><b>Differences:</b></p> <ul style="list-style-type: none"> <li>• New diagnosis</li> <li>• Disclosure to partner</li> <li>• Disclosure to primary caregiver</li> </ul> <p><b>Similarities:</b></p> <ul style="list-style-type: none"> <li>• Disclosure to family and peers</li> </ul>
<b>FAMILY SUPPORT</b>	<ul style="list-style-type: none"> <li>• Living with parents or caregivers, who typically know adolescent’s HIV status so can offer support</li> </ul>	<ul style="list-style-type: none"> <li>• Support system for HIV depends on disclosure</li> </ul>
<b>ECONOMIC SUPPORT</b>	<ul style="list-style-type: none"> <li>• May be unstable if adolescent has been orphaned</li> </ul>	<ul style="list-style-type: none"> <li>• May have few resources (money, information, experience) if adolescent has left home</li> </ul>
<b>ART</b>	<p><b>Differences:</b></p> <ul style="list-style-type: none"> <li>• Often on ART for many years</li> </ul> <p><b>Similarities:</b></p> <ul style="list-style-type: none"> <li>• Adherence challenges in adolescence</li> </ul>	<p><b>Differences:</b></p> <ul style="list-style-type: none"> <li>• May not be needed yet</li> </ul> <p><b>Similarities:</b></p> <ul style="list-style-type: none"> <li>• Adherence challenges in adolescence</li> </ul>
<b>STIGMA/“BLAME”</b>	<ul style="list-style-type: none"> <li>• Less likely to be blamed</li> <li>• Considered “innocent”</li> </ul>	<ul style="list-style-type: none"> <li>• More likely to be blamed because of “irresponsible” behaviour</li> </ul>

Adapted from:

WHO. 2010. IMAI One-day Orientation on Adolescents Living with HIV.

Republic of Zambia, Ministry of Health. 2010. *Guidelines for Antiretroviral Therapy for HIV in Infants and Children in Zambia, Second Edition, 2010* pg 58.



### **Trainer Instructions**

**Step 6:** Allow 5 minutes for questions and answers on this session.

## Session 3.2

# The Package of Adolescent HIV Care and Treatment Services



**Total Session Time:** 175 minutes (2 hours, 55 minutes)



### Trainer Instructions

Slides 17-18

**Step 1:** Review the session objectives, listed below.

**Step 2:** Ask participants if they have any questions before moving on.

### Session Objectives

**After completing this session, participants will be able to:**

- Discuss the importance of comprehensive care for ALHIV.
- Define the package of HIV-related care and treatment for adolescents.



### Trainer Instructions

Slides 19-24

**Step 3:** Ask participants to raise their hand if they have completed training in **paediatric** HIV care and treatment. Then ask who has completed training in **adult** HIV care and treatment.

Remind participants that adolescent HIV care and treatment draws from the knowledge and skills learned in both paediatric and adult training, and that participants should have already completed these trainings before attending this adolescent training.

**Step 4:** Ask participants to recall the key differences and similarities between adolescent HIV care and treatment and both paediatric and adult HIV care and treatment. Stress the point that adolescents are not entirely big children or little adults and that the care of adolescents depends on their age and development.

Tell participants that in this session, we will focus briefly on the clinical components of adolescent HIV care and treatment, but that they should refer to national guidelines and training

packages for paediatric and adult care and treatment for more detailed information.



### **Make These Points**

- As with children and adults, adolescent HIV care and treatment includes a broad package of services and support — much more than ART alone. Adolescent services should be age- and developmentally-appropriate and responsive to the needs of both perinatally and behaviourally infected clients. The package of care should also emphasize the importance of retention in care — whether or not the client is on ART, as well as adherence to care and medicines.
- As with HIV care and treatment for clients of any age, it is important to provide family-focused care to adolescents. Healthcare workers should always ask adolescents about their living and family situations, and when appropriate, engage family members in care and treatment (for their own care and treatment or as supporters to the adolescent client). When appropriate healthcare workers should also ask about partners and encourage steady partners to come to the clinic for education and testing.
- “One-stop shopping” (that is, the location of multiple services in one building, also referred to as “co-location” of services) is important to meet the needs of adolescents, who are unlikely to go from place to place to access needed services. It is also important that services are youth-friendly to encourage retention in care.
- In this session, we will focus primarily on reviewing the clinical care for ALHIV. Psychosocial and adherence support needs of ALHIV will be discussed in detail in subsequent modules.

## **Overview of the Package of Care for ALHIV<sup>1</sup>**

As discussed in the last session, adolescents with perinatally-acquired HIV have typically — but not always — been in care since they were young. Their experience in HIV care and treatment often started when they were children, under the care of healthcare workers with expertise in paediatrics who were steered by paediatric guidelines. As adolescents, clients with perinatally-acquired HIV have typically been on ART for many years and may even be on a 2<sup>nd</sup> or 3<sup>rd</sup> line regimen. Often these adolescents look young for their age and — due to delays in development and overprotection by caregivers — are often young socially as well.

Whereas young people infected with HIV as adolescents may be quite different, they maybe socially experienced, possibly more so than many of their peers, but relatively inexperienced in terms of dealing with the healthcare system. Adolescents with behaviourally-acquired HIV are

typically treated as adults and the treatment is directed by adult guidelines.

Regardless of how long they have been infected or how they acquired HIV, the package of care for all ALHIV is very similar. While the components of the adolescent package of HIV care closely resemble those of the adult package of care, how they are delivered can have an impact on their uptake and success. To be effective, the adolescent package of care must ensure:

- Integration of services
- That services are age and developmentally appropriate
- That they are responsive to the needs of both perinatally infected adolescents, as well as those infected later in childhood or adolescence
- That services are empowering, in other words, that they encourage adolescents to take responsibility (as they are developmentally able) for their own health by taking responsibility for their care, treatment and for living positively
- That there is an emphasis on both care and treatment, and retaining adolescents not eligible for ART in care

#### **The importance of one-stop shopping for ALHIV**

Increase adolescent clients' ability to access and benefit fully from these services by:

- Ensuring services are integrated or, at least co-located — sometimes called “**one-stop shopping**”
- Ensuring services are youth-friendly (see Module 2)

The goals of comprehensive HIV care are to:

- Reduce HIV-related illness and death,
- Improve quality of life,
- Improve the lives of families and communities affected by HIV, and
- Prevent further spread of HIV.

## **The Importance of Family-focused Care**

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- Family-focused care means that all members of the multidisciplinary care team think about the needs of all family members, and not just those of the adolescent client.
- It also means thinking about the linkages between the individual client, the client's family, and the community as a whole.
- Depending on the client's age and family situation, healthcare workers should make it a normal practice to ask clients about caregivers and other family members and encourage them to bring family members to the clinic for services, if needed. Healthcare workers can provide family members with ongoing education and information on HIV care and treatment, adherence counselling and support, and general support on caring for ALHIV.
- With older adolescents, healthcare workers should also enquire about partners and children. When the adolescent is ready, he or she should be encouraged and supported to bring his or her partner to the clinic

for information on HIV, safer sex — including condoms use — and HIV testing.

**Remember:** Adolescent's day-to-day lives include their families, partners, children, friends and other community members, so it is important to ask about them at every visit!



### **Trainer Instructions**

Slides 25-37

#### **Step 5:**

Provide an overview of the clinical assessment. Note that there are three clinical assessment checklists: the 1<sup>st</sup> is the listing of activities that are conducted at the initial, or baseline, visit. The 2<sup>nd</sup> and 3<sup>rd</sup> list the steps conducted at all follow-up visits — depending on whether or not the client is on ART. There is much overlap between the three lists.

Ask participants:

- *What activities are conducted during the baseline clinical assessment?* (Record their responses on a flip chart and fill in using the content below.)
- *What are the key activities during a follow-up clinical assessment?* (Record their responses on flip chart.)

Feel free to underline points mentioned as part of the baseline clinical assessment that also appear on the follow-up visit clinical assessment list (rather than writing them twice). Fill in using the content below.

#### **Step 6:**

Provide an overview of the laboratory assessments, referring participants to “Appendix 3A: Clinical and Laboratory Monitoring for ALHIV”.

(optional) Ask the adolescent co-trainer to share more about his or her clinical and laboratory monitoring schedule, including how he or she remembers to attend these appointments.



### **Make These Points**

- The clinical assessment for a client with HIV needs to be thorough and include a focus on clinical, laboratory, nutrition and social parameters.
- CD4 cell count should be measured at time of diagnosis and 6 monthly, regardless of whether the ALHIV is on ART or not. Measure CD4 more

often if CD4 is approaching the threshold for starting ART, just prior to starting ART and if a new clinical staging event develops.

## Comprehensive Care for ALHIV

The care of the child with HIV is directed by paediatric guidelines, but as the child ages and develops, his or her care transitions to follow the adult HIV guidelines, with the care of adolescents often guided by one or the other or both. Although the paediatric and adult guidelines have many similarities (for example, criteria for ART initiation for the child over 5 years of age is the same as for an adult), it also allows the healthcare worker flexibility to tailor to the child a package of care that meet his or her needs.

Comprehensive care for ALHIV includes the provision of the services listed in the clinical assessment checklists in Table 3.2, Table 3.3, and Table 3.4, below. The first is a listing of steps conducted at the initial, or baseline, visit, as many adolescents with perinatally-acquired HIV have been in care for years, they will have undergone this baseline assessment as infants or children. As such the checklist in Table 3.2 is more for the young person who acquired HIV as an adolescent. Note that it may take several visits to complete all activities on the baseline clinical assessment.

The 2<sup>nd</sup> (Table 3.3) is the list of steps conducted at follow-up visits for clients *not* on ART, the 3<sup>rd</sup> table (Table 3.4) is a list of steps conducted at follow-up visits for clients on ART.

**Table 3.2: Key steps — baseline visit**

✓	Steps
	<ul style="list-style-type: none"> <li>• Confirm HIV infection status</li> </ul>
	<ul style="list-style-type: none"> <li>• Take a complete medical and social history, including prenatal, birth and family history. Enquire about disclosure to the adolescent (if perinatally infected) or disclosure to others (if HIV was acquired during adolescence) and HIV and treatment status of the mother, father and siblings.</li> </ul>
	<ul style="list-style-type: none"> <li>• Identify concomitant medical conditions (for example, hepatitis B or C infection, other co-infections or OIs, pregnancy in adolescent girls)</li> </ul>
	<ul style="list-style-type: none"> <li>• Enquire about concomitant medication, including cotrimoxazole (CTX), oral contraceptives, and traditional or herbal therapies</li> </ul>
	<ul style="list-style-type: none"> <li>• Conduct physical examination, including Tanner staging, STI screening for sexually active adolescents, skin exam (tattoos, bruises, acne), scoliosis evaluation</li> </ul>
	<ul style="list-style-type: none"> <li>• Prevent, diagnose and treat OIs and other concomitant conditions, including tuberculosis (discussed briefly in this module), diarrhoea, malaria and pregnancy in sexually active adolescents.</li> </ul>
	<ul style="list-style-type: none"> <li>• Assess growth and nutrition (weight, height), as appropriate for</li> </ul>

	age
	<ul style="list-style-type: none"> <li>Assess development and neurodevelopment, as appropriate for age</li> </ul>
	<ul style="list-style-type: none"> <li>Review immunisation status of adolescent</li> </ul>
	<ul style="list-style-type: none"> <li>Undertake a nutritional status assessment, including assessment of the quality and quantity of intake</li> </ul>
	<ul style="list-style-type: none"> <li>Conduct psychosocial assessment, counselling, and support (discussed in Modules 5, 6, and 7). See “Appendix 3B: HEADSS Interview Questions” for guidance.</li> </ul>
	<ul style="list-style-type: none"> <li>Assess WHO clinical stage. If not on ART, determine whether the adolescent meets the clinical criteria for ART initiation. If already on ART, determine if any new stage 3 or 4 events have occurred since ART was initiated.</li> </ul>
	<ul style="list-style-type: none"> <li>For those eligible for ART by clinical criteria (WHO stage 3 or 4), consider initiating ART preparation (see “Appendix 8A: Key Points — Adherence Visit 1” in Module 8)</li> </ul>
	<ul style="list-style-type: none"> <li>Discuss findings</li> </ul>
	<ul style="list-style-type: none"> <li>Advise and guide (reinforce and support adherence to ART and CTX — if applicable, nutrition, when to seek medical care, medication side effects, adherence, positive living and legal rights; provide referrals for follow up)</li> </ul>
	<ul style="list-style-type: none"> <li>Schedule lab tests indicated (discussed briefly below)</li> </ul>
	<ul style="list-style-type: none"> <li>Schedule next visit</li> </ul>

**Table 3.3: Key steps — follow-up visit, clients NOT on ART**

✓	Steps
	<ul style="list-style-type: none"> <li>Assess growth and nutrition (weight, height), as appropriate for age</li> </ul>
	<ul style="list-style-type: none"> <li>Assess development and neurodevelopment, as appropriate for age</li> </ul>
	<ul style="list-style-type: none"> <li>Review interim medical history</li> </ul>
	<ul style="list-style-type: none"> <li>Conduct physical examination, including Tanner staging, STI screening for sexually active adolescents, skin exam (tattoos, bruises, acne), scoliosis evaluation</li> </ul>
	<ul style="list-style-type: none"> <li>Prevent, diagnose and treat OIs and other concomitant conditions, including tuberculosis (discussed briefly in this module), diarrhoea, malaria and pregnancy in sexually active adolescents.</li> </ul>
	<ul style="list-style-type: none"> <li>Review concomitant medications (consider drug interactions, make dose adjustments if pre-pubescent adolescent)</li> </ul>
	<ul style="list-style-type: none"> <li>If on CTX (discussed in this module) provide refill, monitor adherence, and address the adolescent’s and/or caregiver’s understanding of and adherence to therapy (discussed in Module 8)</li> </ul>
	<ul style="list-style-type: none"> <li>Assess WHO clinical stage.</li> </ul>
	<ul style="list-style-type: none"> <li>Review clinical findings at this visit and laboratory findings (include CD4 cell count) from recent visits and consider</li> </ul>

	eligibility for ART and CTX (discussed in this module). If eligible for ART, initiate adherence preparation (discussed in Module 8), which takes 3 visits to cover
	<ul style="list-style-type: none"> <li>• Provide nutrition counselling and support, as indicated (discussed in Module 9)</li> </ul>
	<ul style="list-style-type: none"> <li>• Conduct psychosocial assessment, counselling, and support, including for disclosure (discussed in Modules 5, 6, and 7). See “Appendix 3B: HEADSS Interview Questions”.</li> </ul>
	<ul style="list-style-type: none"> <li>• Discuss positive living and positive prevention (discussed in Modules 9 and 10)</li> </ul>
	<ul style="list-style-type: none"> <li>• Provide sexual and reproductive health information, screening, diagnosis, treatment, counselling, and supplies (discussed in Module 10)</li> </ul>
	<ul style="list-style-type: none"> <li>• Provide additional support for adolescent clients who are switching providers or transitioning into adult care (discussed in Module 12)</li> </ul>
	<ul style="list-style-type: none"> <li>• Provide education, care, and support for family members and/or partner (discussed throughout this curriculum)</li> </ul>
	<ul style="list-style-type: none"> <li>• Discuss findings</li> </ul>
	<ul style="list-style-type: none"> <li>• Advise and guide (reinforce and support adherence to ART and CTX — if applicable, nutrition, when to seek medical care, medication side effects, adherence, positive living and legal rights; provide referrals for follow up)</li> </ul>
	<ul style="list-style-type: none"> <li>• Schedule lab tests indicated (discussed briefly below)</li> </ul>
	<ul style="list-style-type: none"> <li>• Schedule next visit</li> </ul>

**Table 3.4: Key steps — follow-up visit, clients on ART**

✓	Steps
	<ul style="list-style-type: none"> <li>• Assess growth and nutrition (weight, height), as appropriate for age</li> </ul>
	<ul style="list-style-type: none"> <li>• Assess development and neurodevelopment, as appropriate for age</li> </ul>
	<ul style="list-style-type: none"> <li>• Review interim medical history</li> </ul>
	<ul style="list-style-type: none"> <li>• Conduct physical examination, including Tanner staging, STI screening for sexually active adolescents, skin exam (tattoos, bruises, acne), scoliosis evaluation, evidence of ART side effects or complications (fat redistribution, skin changes)</li> </ul>
	<ul style="list-style-type: none"> <li>• Prevent, diagnose and treat OIs and other concomitant conditions, including tuberculosis (discussed briefly in this module), diarrhoea, malaria and pregnancy in sexually active adolescents.</li> </ul>
	<ul style="list-style-type: none"> <li>• Review concomitant medications (consider drug interactions, make dose adjustments if pre-pubescent adolescent)</li> </ul>
	<ul style="list-style-type: none"> <li>• Provide refills for ART and CTX, monitor adherence, and address the adolescent’s and/or caregiver’s understanding of and adherence to therapy (discussed in Module 8)</li> </ul>
	<ul style="list-style-type: none"> <li>• Assess WHO clinical stage, determine if any new stage 3 or 4</li> </ul>

	events have occurred since ART was initiated. Assess CD4 count, determine if treatment failure has occurred.
	<ul style="list-style-type: none"> <li>• Provide nutrition counselling and support, as indicated (discussed in Module 9)</li> </ul>
	<ul style="list-style-type: none"> <li>• Conduct psychosocial assessment, counselling, and support, including for disclosure (discussed in Modules 5, 6, and 7). See “Appendix 3B: HEADSS Interview Questions”.</li> </ul>
	<ul style="list-style-type: none"> <li>• Discuss positive living and positive prevention (discussed in Modules 9 and 10)</li> </ul>
	<ul style="list-style-type: none"> <li>• Provide sexual and reproductive health information, screening, diagnosis, treatment, counselling, and supplies (discussed in Module 10)</li> </ul>
	<ul style="list-style-type: none"> <li>• Provide additional support for adolescent clients who are switching providers or transitioning into adult care (discussed in Module 12)</li> </ul>
	<ul style="list-style-type: none"> <li>• Provide education, care, and support for family members and/or partner (discussed throughout this curriculum)</li> </ul>
	<ul style="list-style-type: none"> <li>• Discuss findings</li> </ul>
	<ul style="list-style-type: none"> <li>• Advise and guide (reinforce and support adherence to ART and CTX — if applicable, nutrition, when to seek medical care, medication side effects, adherence, positive living and legal rights; provide referrals for follow up)</li> </ul>
	<ul style="list-style-type: none"> <li>• Schedule lab tests indicated (discussed briefly below)</li> </ul>
	<ul style="list-style-type: none"> <li>• Schedule next visit</li> </ul>

Further guidance of most of these activities can be found in both the “Guidelines for Antiretroviral Therapy for HIV in Infants and Children in Zambia” and the “Adult and Adolescent Antiretroviral Therapy Protocols, 2010”.

## Laboratory Monitoring

Laboratory assessments should be conducted at baseline (that is, entry into HIV care) and as indicated in “Appendix 3A: Clinical and Laboratory Monitoring for ALHIV”. **The unavailability of laboratory monitoring, including CD4 and chemistries, should NOT prevent adolescents from receiving ART.**

Note the following:

- **CD4** should be measured at the time of diagnosis, AND
  - **Adolescents not yet eligible for ART:** monitor every 6 months; but 3 monthly as CD4 count approaches threshold for starting ART.
  - **Adolescents on ART:** measure just prior to starting ART (if previous CD4 was measured more than 3 months ago) and every 6 months thereafter.
  - **All adolescents:** measure CD4 if a new clinical staging event develops, including growth faltering and neurodevelopmental delays.



### **Trainer Instructions**

Slides 38-62

- Step 7:** Provide an overview of CTX. Engage participants by asking:
- *When is CTX initiated in newly diagnosed adolescent clients?*
  - *When would you discontinue CTX?*

Summarise the contraindications and dosing for CTX.

- Step 8:** Transition to a discussion of ART in ALHIV. Start by providing a brief overview of the benefits of ART then discuss the issues that need to be considered before starting ART. Then ask participants:
- *What is the immunological criteria to start ART?*
  - *What are the social issues that need to be considered before starting ART?*
  - *What is the first line ART regimen for pre-pubertal adolescents (that is, the first line ART regimen according to the “Guidelines for Antiretroviral Therapy for HIV in Infants and Children in Zambia”)*
  - *How does the first line ART regimen differ for post-pubertal adolescents?*

(optional) Ask the adolescent co-trainer to share about his or her ART regimen, including dosing, side effects, challenges, etc.

- Step 9:** Remind participants that adherence to both care and medications are crucial for ALHIV. Considerations for supporting ALHIV with adherence will be discussed in detail in Module 8.

- Step 10:** Ask participants:
- *How often do adolescents on ART need to return to the clinic after starting ART?*
  - *How often do adolescents not yet eligible for ART need to return to the clinic?*

Fill in using the content below.



### **Make These Points**

- Initiate CTX when CD4 count is  $<350\text{cells/mm}^3$  regardless of clinical stage, or if CD4 count is unavailable start when adolescent is in clinical

stage 2, 3 or 4.

- CTX may be discontinued in an adolescent on ART if he or she shows evidence of immune recovery of CD4  $>350\text{cells}/\text{mm}^3$  after at least 6 months of treatment.
- According to the Zambia guidelines, the decision to initiate ART is based on immunological and clinical criteria (CD4  $\leq 350$  or WHO stage 3 or 4) and informed by social considerations, such as ability to adhere to the regimen.
- The recommended first line ART regimen depends on whether the ALHIV is considered pre- or post-pubertal. For those who are pre-pubertal, the first line regimen is AZT + 3TC + NVP or EFV. Whereas in post-pubertal adolescents it is TDF + FTC + NVP or EFV.
- Frequency of clinical monitoring depends on whether adolescents are pre- or post-pubescent. If pre-pubescent, then they should return every 3 months. Post-pubescent adolescents need to return every 6 months. For both groups of adolescents, follow up is more frequent for those who have just started ART or are near to the CD4 threshold for starting ART.

## **Cotrimoxazole (CTX)**

CTX prophylaxis, often referred to simply as CTX, is a well-tolerated, cost-effective and life saving intervention for people living with HIV. It should be implemented as an integral component of chronic care for adolescents on ART as well as a key element of pre-ART care.

### **Initiating CTX**

Indications for CTX

- Clinical criteria: Start CTX when adolescent is in clinical stage 2, 3 or 4 regardless of CD4
- Immunologic criteria: Start CTX when CD4 count is  $<350\text{cells}/\text{mm}^3$  regardless of clinical stage

### **Discontinuing CTX**

- CTX can be discontinued in an adolescent on ART if he or she shows evidence of immune recovery of CD4  $>350\text{cells}/\text{mm}^3$  after at least 6 months of treatment.
- In situations where CD4 is not available, CTX can be discontinued when there is evidence of good clinical response to ART (absence of clinical symptoms after at least one year of therapy), good adherence and secure access to ART.
- If CTX is discontinued, it should be restarted if the CD4 falls below 350 cells/ $\text{mm}^3$  or if the patient has a new or recurrent WHO clinical Stage 2, 3, or 4 condition.

## Discontinuation of CTX due to adverse events

CTX should be discontinued if the adolescent experiences drug-related adverse events such as jaundice, extensive exfoliative rash, Stevens-Johnson syndrome, severe anaemia or pancytopenia. Such drug-related adverse events are unusual.

## Contraindications to CTX

Contraindications of CTX include:

- Adolescents with history of severe and life-threatening adverse reactions — grade 3 and 4 to CTX or other sulfa drugs — should not be prescribed CTX: dapsone 100 mg/day should be given as an alternative. See “Adult and Adolescent Antiretroviral Therapy Protocols, 2010” additional information, including guidance on desensitising those with history of grade 1 or 2 reaction to CTX.
- Severe liver disease
- Severe renal insufficiency

**Table 3.5: Dosing for CTX**

Recommended once daily dose by age	Suspension	Child tablet (100mg/20mg)	Single strength adult tablet (400mg/80mg)
10–14 years (or 15–30 kg) 400 mg sulfamethoxazole/ 80 mg trimethoprim	10 ml	4 tablets	1 tablet
>14 years (or >30 kg) 800 mg sulfamethoxazole/ 160 mg trimethoprim	N/A	N/A	2 tablets

CTX can be safely continued or initiated during pregnancy, regardless of stage of pregnancy, and breastfeeding.

Source: Republic of Zambia, MoH, Guidelines for Antiretroviral Therapy for HIV in Infants and Children in Zambia, Second Edition, 2010.

## When to Start ART in ALHIV

ART helps HIV-infected adolescents to preserve, and enhance, their immune systems — reducing their risk of OIs, restoring growth, improving mental functioning, and overall quality of life. By adolescence, most clients with perinatally-acquired HIV will already be on CTX. The decision to start ART in an adolescent client relies on clinical and immunological assessment, as well as evaluation of the adolescent’s social environment.

## Social issues to consider before initiating ART

Before initiating ART, healthcare workers should also think about:

- Readiness for ART: The adolescent understands what ARVs are, how they are to be taken, and is ready to take on this life-long commitment.
- Ability and willingness of adolescent to return for regular follow up.
- How well the adolescent has done taking CTX daily.

- **Adherence/treatment preparation:** The healthcare worker will have discussed adherence with the adolescent and worked out a plan with the adolescent for him or her to take ARVs every day exactly as prescribed. The “Adult and Adolescent Antiretroviral Therapy Protocols 2010” recommend that all clients initiating ART commit to “perfect” adherence. Given the nature of adolescence, healthcare workers should, upon completion of all three adherence preparation visits, at least get from the adolescent a commitment to excellent adherence, even if that commitment turns out to be easier said than done (see Module 8).
- **Family and peer support:** Ideally, adolescent clients would have family members, parents, caregivers, or peers that understand their HIV diagnosis and the implications of ART, including the importance of adherence for life, and support them to take their ARVs every day.

### **Immunological criteria to start ART**

The criteria to initiate ART is the same in all adolescent patients and adults:

- **CD4  $\leq$ 350 or WHO stage 3 or 4**
- **CD4  $>$ 350 if:**
  - The adolescent is the HIV positive partner in a discordant couple
  - The adolescent has hepatitis B virus infection (chronic hepatitis B as demonstrated by the presence of HBsAg) **and** elevated ALT or AST **or** has signs of liver cirrhosis. (If the adolescent is HBsAg positive but has normal baseline ALT or AST, recheck both ALT or AST and HBsAg in 6–12 months. If ALT or AST are elevated, or persistent HBsAg then start ART.)

### **Clinical criteria to start ART**

- **All adolescent clients** with stage 3 and 4 disease should start ART, regardless of CD4 count.
- Asymptomatic or mildly symptomatic adolescents (i.e. those in stages 1 and 2) should be considered for ART when immunological values fall near the threshold values. A drop below threshold values should be avoided.

### **Prior to initiating ART ensure that:**

- Adolescents who know their status have disclosed to someone they trust; adolescents with perinatally-acquired HIV know their HIV status (i.e, have been disclosed to). Ensure that disclosure is documented
- CTX is initiated
- Minimum baseline laboratories are completed (see previous section and “Appendix 3A: Clinical and Laboratory Monitoring for ALHIV”)
- The adolescent has none of the following signs of un-resolved opportunistic infections (OIs):
  - Persistent fever ( $>$ 14 days)
  - Persistent cough ( $>$ 14 days)
  - Severe persistent headache ( $>$ 14 days)
  - Anaemia (Hgb  $<$  8 or Hct  $<$  24)

- Weight loss > 10%

If ANY of the above five symptoms are PRESENT then investigate and treat as appropriate (see “Adult and Adolescent Antiretroviral Therapy Protocols, 2010”).

- Initiate ART 2 weeks after documented response to treatment
- If no clear diagnosis obvious from diagnostic test, then consult an HIV Specialist before initiating ART

For more information, see “Appendix 3A: Clinical and Laboratory Monitoring for ALHIV”, “Appendix 3C: WHO Staging for Children with Established HIV Infection” and “Appendix 3D: WHO Clinical Staging of HIV Disease in Adults and Adolescents”.

## **Recommended First-Line ART Regimens for ALHIV**

### **Introduction to ARV regimen**

ARV regimen and dosing for adolescent clients depend on his or her physical maturity, based on the Tanner scale (see “Appendix 2A: Tanner Scale”). The Tanner scale defines physical measurements of development, based on external primary and secondary sexual characteristics.

- Adolescents who are at **Tanner stages I, II and III** are pre-pubertal; regimens and dosages should be guided by the paediatric guidelines (“Guidelines for Antiretroviral Therapy for HIV in Infants and Children in Zambia”). These clients require close clinical monitoring as adolescence is a time of hormonal changes and rapid growth.
- Adolescents who are at **Tanner stages IV and V** are post-pubertal and should be treated according to the adult ARV guidelines.

As a general rule, those who acquire HIV during their adolescent years, are treated according to the adult ARV guidelines, regardless of Tanner stage.

### **Pre-pubertal adolescents**

For adolescents (Tanner scale I, II or III), first line ART regimens contains NVP or EFV plus a “backbone” consisting of 2 NRTIs. See Table 3.6 for preferred and alternative first line regimens.

**Table 3.6: Regimens for children and pre-pubertal adolescents (Tanner scale I, II or III)**

	Regimen	
	NRTI backbone	NNRTI component
Preferred 1 <sup>st</sup> line	AZT + 3TC +	NVP or EFV <sup>1, 2</sup>
Alternative 1 <sup>st</sup> line <sup>3</sup>	ABC + 3TC +	NVP or EFV <sup>1, 2</sup>
2 <sup>nd</sup> Alternative 1 <sup>st</sup> line <sup>4</sup>	d4T + 3TC +	NVP or EFV <sup>1, 2</sup>
1	The preferred regimen for adolescents with tuberculosis is EFV + the 2 NRTI backbone.	
2	The use of EFV should be avoided in adolescent girls due to the fact that it may cause	

foetal harm in the first trimester of pregnancy. If possible, adolescent girls taking EFV should be switched to a NVP-based or other regimen or counselled on and provided with a contraceptive method.

- 3 Use the alternative 1<sup>st</sup> line regimen only if there are contraindications to AZT (for example, severe anaemia, <8g/dl; or neutropenia, <500 cells/mm<sup>3</sup>) or AZT availability cannot be assured.
- 4 Due to its unfavourable toxicity profile and its selection for unfavourable resistance patterns, use of d4T should be minimised; therefore d4T/3TC should only be used as a last resort for initiating infants on ART if the use of AZT or ABC is contraindicated or cannot be assured.

Note that the 2010 guidelines call for the phasing out of used of d4T-containing regimens, unless AZT or ABC are contraindicated or not assured. The guidelines provide advice on drug substitution for adolescents currently on d4T.

Dosing in pre-pubertal adolescents is usually based on either weight or body surface area. As these change with growth, drug doses must be adjusted at each visit to avoid the risk of under-dosing. For additional information on dosing and regimens for specific scenarios (for example, patients with hepatitis), see “Guidelines for Antiretroviral Therapy for HIV in Infants and Children in Zambia”, Section 6 and Annex G.

### Post-pubertal adolescents and adults

For post-pubertal adolescents (Tanner scale IV and V), the 2010 first line ART regimens includes a TDF + FTC “backbone”. TDF + FTC + EFV is now the preferred first line regimen due to long-term potency, favourable mutation pathway, and lower incidence of anaemia. See Table 3.7 for preferred and alternative first and second line regimens.

**Table 3.7: Regimens for post-pubertal adolescents (Tanner scale IV and V) and adults**

	Regimen	
	NRTI backbone	NNRTI component
Preferred 1 <sup>st</sup> line	TDF + FTC +	NVP <sup>1</sup> or EFV <sup>2</sup>
Alternative 1 <sup>st</sup> line <sup>3</sup>	ABC + 3TC +	NVP <sup>1</sup> or EFV <sup>2</sup>
Preferred 2 <sup>nd</sup> line <sup>4</sup>	AZT <sup>5</sup> + 3TC +	LPV/r
<p>1 Avoid use of NVP either of the following groups of patients:</p> <ul style="list-style-type: none"> <li>• Women who have had exposure to sdNVP without tail coverage with 7 days of AZT + 3TC within the last 12 months (for PMTCT). Instead do not use an Efavirenz containing regimen, instead use LPV/r. If unsure whether tail coverage for sdNVP was provided then use LPV/r</li> <li>• Patients with CD4 greater than 250</li> </ul> <p>2 The use of EFV should be avoided in women due to the fact that it may cause foetal harm in the first trimester of pregnancy. If possible, women taking EFV should be switched to a NVP-based or other regimen or counselled on and provided with a contraceptive method.</p> <p>3 TDF has been associated with renal toxicity: if CrCl &lt;50 ml/min, initiate therapy with ABC/3TC (the alternative 1st line regimen)</p> <p>4 This is the preferred 2nd line regimen for patients failing TDF-based 1st line regimen. Other possible NRTI backbones for 2<sup>nd</sup> line regimens include AZT + TDF <b>or</b> AZT + FTC. The alternative 2<sup>nd</sup> line regimen is d4T + 3TC + LPV/r, but as d4T is associated with long term toxicity, it should be used only if AZT cannot be tolerated.</p>		

5 AZT is not recommended in patients with Hgb <10. Delay ART until anaemia is treated or use alternative NRTI combination (some of the alternatives are listed in note 4, above).

Recommendations for paediatric patients transitioning to adult care:

- Continue stable patients without signs of toxicity or clinical failure on current regimen: (AZT, ABC or d4T) + 3TC + (NVP or EFV)
- Switch patients with signs of toxicity but not clinical failure to proposed first line regimen: TDF + FTC + either NVP or EFV
- Switch patients with signs of clinical failure from AZT, ABC or d4T-containing regimen to TDF + FTC + LPV/r

See “Appendix 3E: ARV Dosages for Post-pubertal Adolescents and Adults”. For additional information, see “Adult and Adolescent Antiretroviral Therapy Protocols, 2010” or consult a local or provincial HIV specialist for guidance on transitioning to the 2010 recommendations.

### **Possible events during the first 6 months**

The first six months on ART are critical. In most adolescents, CD4 cell counts rise with the initiation of ART, increase over the course of the first year of treatment, reach a plateau and then continue to rise further over the second year. But, some fail to respond as expected or may even exhibit clinical deterioration.

- Complications in the first few weeks following the initiation of ART are seen most commonly in those with severe immunodeficiency.
- Apparent failure to improve in an adolescent with advanced HIV disease does not necessarily reflect a poor response to ART; it takes time for HIV viral replication to be controlled by ART and for the youth’s immune system to recover.
- As an adolescent with advanced disease recovers immune function, there is risk of immune reconstitution inflammatory syndrome (IRIS). IRIS — which most often occurs within the first weeks to months after initiation of ART — is a complication caused by reactivation of the immune system. IRIS can present as a flare-up of symptoms when the recovering immune system begins to respond to an existing infection, for example, TB. The response is not due to failure of ART, but rather to its success and the resulting immune reconstitution. When IRIS is suspected, consult a clinician experienced in managing adolescents with HIV.
- Allow sufficient time (at least six months on therapy) before judging the effectiveness of a regimen. Supporting adherence during this period is

#### **Key signs of an adolescent’s response to ART include:**

- Improvement in growth in adolescents who have been failing to grow
- Improvement in neurological symptoms and development (if the adolescent has experienced delays in the achievement of developmental milestones)
- Decreased frequency of infections (bacterial infections, oral thrush and/or other OIs)

critical and, in such cases, switching of ARV regimen would be inappropriate.

- Persistent failure to see a CD4 response should alert the healthcare worker to potential adherence problems or non-response to ART. In this case, viral load determination can be useful as can consultation with a clinician experienced in managing adolescents with HIV.

## Supporting Adherence to Care and Treatment among ALHIV

Adherence to both care and medicines are the cornerstones of effective and successful HIV care. Adolescents often face unique challenges with adherence that are different than paediatric or adult clients. Adherence preparation, assessment, and counselling and support for ALHIV is discussed in detail in Module 8.

### Frequency of clinical monitoring

- **Adolescents on ART:** the frequency of clinical monitoring will depend on response to ART. At a minimum, after starting ART, **follow-up visits should occur at weeks 2, 4, 8, 12, and then every 3 months** once the adolescent has stabilised on ART.
- **Adolescents not yet eligible for ART:**
  - **Pre-pubescent adolescents:** follow-up visits should occur every 3 months at a minimum
  - **Post-pubescent adolescents:** follow-up visits should occur every 3 months if CD4 count is between 350–500 and every 6 months if CD4 cell count is greater than 500.



### Trainer Instructions

Slides 63-67

**Step 11:** Provide a brief overview of toxicities to ART referring participants to the guidelines for additional information. Note that the potential for an adverse reaction to ART is possible and should be mentioned in pre-ART adherence counselling session.

**Step 12:** Briefly discuss treatment failure. Ask participants:

- *What is the definition of treatment failure?*
- *There are five things that need to be excluded before we can conclude that a client's assumed lack of response to ART if real, can anyone name any one of these five conditions?*

(optional) Invite the adolescent co-trainer to discuss any experience that he or she has had with toxicities or treatment failure.



### Make These Points

- Severe life-threatening toxicities require discontinuation of all ARV drugs, whereas those that are mild or moderate do not require discontinuation (but may require drug substitution).
- The healthcare worker needs to ensure that the ALHIV has been adherent to his or her regimen before considering the possibility of treatment failure.
- Given the limited number of ART regimens available in Zambia, it is important to:
  - Ensure a very high likelihood of adherence before initiating ART by providing ART preparation as described in the “Adult and Adolescent Antiretroviral Therapy Protocols, 2010” and summarised in Module 8.
  - Limit drug discontinuation to those experiencing grade 3 or 4 toxicities.
  - Investigate all possible explanations for treatment failure before switching to a new regimen.

## Toxicities

Toxicity can be monitored clinically, based on adolescent/caregiver reporting and physical examination, and can also be assessed by a limited number of laboratory tests. Drug toxicities generally fall into one of the following 3 categories:

- **Mild toxicities** do not require discontinuation of therapy or drug substitution, and symptomatic treatment may be given (for example, antihistamines for a mild rash).
- **Moderate or severe toxicities** may require substitution with a drug in the same ARV class but with a different toxicity profile, or with a drug in a different class, but do not require discontinuation of all ART.
- **Severe life-threatening toxicities** require discontinuation of all ARV drugs, and the initiation of appropriate supportive therapy until the patient is stabilised and the toxicity is resolved. NNRTIs have a longer half-life than NRTIs, and stopping all first-line drugs simultaneously may result in exposure to sub-therapeutic levels of the NNRTI and subsequently to the development of NNRTI resistance. However, if a child has a life-threatening toxicity, all ARV drugs should be stopped simultaneously until the patient is stabilised.

Refer to the “Guidelines for Antiretroviral Therapy for HIV in Infants and Children in Zambia” and/or “Adult and Adolescent Antiretroviral Therapy Protocols 2010” for additional information about dealing with toxicities or to a local HIV specialist.

## Considerations for adherence

Regardless of their severity, adverse reactions may affect adherence to therapy. A proactive approach to managing toxicity is recommended:

- Before initiating ART, discuss the potential side-effects.
- During the early stages of treatment, offer support during minor and moderate adverse reactions.

Many ARV drug toxicities are time-limited and resolve spontaneously even when the same ART regimen is continued.

## Treatment Failure

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In the absence of viral load measurement, clinical criteria and CD4 count can be used to identify treatment failure. Therefore, when treatment failure is suspected, confirm that:

- The adolescent has been on ART for at least 24 weeks. The adolescent has been adherent, that is, that he or she has taken nearly all of his ARVs exactly as prescribed. If adherence has not been optimal, then the first course of action is to keep the adolescent on the same regimen, but counsel and support adherence.
- Any inter-current infection or major clinical event has been treated and resolved.
- IRIS has been excluded.
- Before considering a change in treatment because of growth failure, ensure that the adolescent is receiving adequate nutrition.

When treatment failure is confirmed (see box below), switching to a new second-line regimen becomes necessary. In the absence of viral load testing, suspected treatment failure should be referred to the most senior/experienced treatment provider for assessment.

### Treatment failure

Where available, confirm treatment failure with viral load testing. Viral load is the only marker that accurately identifies patients with **virologic failure** or suppression. **Clinical** and **immunologic** criteria can raise the suspicion of virologic failure and be useful to prompt further investigation and help clinical decision making in the absence of viral load monitoring.

**Clinical criteria of treatment failure:** New or recurrent stage 3 or 4 event at least 6 months after starting ART

- Condition must be differentiated from immune reconstitution inflammatory syndrome (IRIS)

**Immunological criteria of treatment failure:**

- Developing or returning to the following immunologic threshold after at least 24 weeks on ART in a treatment-adherent adolescent:
  - CD4 count of <100
- Note: Rule out concomitant infection as a cause of transient CD4 cell

decrease or slow increase

**Virological criteria of treatment failure:** According to the Zambia “Adult and Adolescent Antiretroviral Therapy Protocols, 2010” virologic failure—defined as VL >1000 copies/ml\*.

If viral load is not available, consult the multidisciplinary team or HIV Specialist for joint decision to either initiate 2<sup>nd</sup> line therapy or monitor patient using clinical and immunologic indicators.

\* For additional information on virologic failure, see the Zambia “Adult and Adolescent Antiretroviral Therapy Protocols, 2010” and “Guidelines for Antiretroviral Therapy for HIV in Infants and Children in Zambia, Second Edition, 2010”.



### **Trainer Instructions**

Slides 67-74

#### **Step 13:**

Discuss TB screening, prevention, and treatment considerations. Start the discussion by asking:

- *Why do you think it is important to discuss TB as part of this training? (Answer: Worldwide, TB is the leading cause of death among HIV infected people.)*
- *How often do you screen for TB? (Answer: at every visit.)*
- *How do you screen for TB?*
- *What is the chemoprophylaxis for TB?*

Then provide a brief overview of treatment consideration in adolescents with TB and HIV.



### **Make These Points**

- There are many steps that can be taken to prevent, screen and provide early treatment for tuberculosis. Excellent TB prevention and early treatment can prevent unnecessary illness and death in people with HIV.

## **Tuberculosis**

People with HIV, including adolescents, are prone to developing OIs and other HIV-related infections, particularly if their CD4 levels drop and they are not on ART. Many OIs can be prevented by ensuring that patients are put on ART and CTX as per guidelines.

Because of its prevalence amongst people with HIV, one OI in particular deserves further discussion: TB. Co-infection with HIV/TB is a major public health threat for people living with HIV and the community. TB threatens the significant health benefits achieved with scale-up of HIV care and treatment. All people living with or at higher risk of HIV in Zambia should be routinely screened for TB and placed on TB treatment if found with to have TB.

## Screening for TB

All ALHIV should be evaluated for contact with a TB source case and for TB symptoms at every visit to a healthcare facility. Key screening questions are included in Table 3.8.

**Table 3.8: TB screening for adolescents in Zambia**

Question	Yes or No
1. Has the patient been coughing for $\geq 2$ weeks?	<input type="checkbox"/> Yes <input type="checkbox"/> No
2. Has the patient been having night sweats for $\geq 3$ weeks?	<input type="checkbox"/> Yes <input type="checkbox"/> No
3. Has the patient lost $\geq 3$ kg during the last 4 weeks?	<input type="checkbox"/> Yes <input type="checkbox"/> No
4. Has the patient been having fever for $\geq 3$ weeks?	<input type="checkbox"/> Yes <input type="checkbox"/> No
5. Has the patient had contact with someone with TB?	<input type="checkbox"/> Yes <input type="checkbox"/> No
<ul style="list-style-type: none"> <li>• If “Yes” to question 1: do sputum tests and refer to clinician for further investigation of TB.</li> <li>• If “No” to question 1 and “yes” to any other question: Refer to clinic clinician for investigation of TB.</li> <li>• If “No” to all questions: repeat screening at next visit.</li> </ul>	

For information on the diagnosis of TB, see “Guidelines for Antiretroviral Therapy for HIV in Infants and Children in Zambia”.

## Prevention of TB with isoniazid preventive therapy

- All HIV-infected adolescents exposed to TB through household contacts, but with no evidence of active disease, should begin isoniazid preventive therapy (IPT).
- The recommended dose of isoniazid (INH) for preventive therapy in HIV co-infection is 10 mg/kg daily for 6 months (maximum 300 mg/day; any adolescent weighing more than 25 kg will receive the maximum dose of 300 mg/day).

## Treatment considerations in adolescents with TB and HIV

- Any adolescent with active TB disease should begin TB treatment immediately, and start ART (if eligible) as soon as tolerated — within 2–8 weeks (pre-pubertal adolescents) or 2–3 weeks (post-pubertal adolescents).
- The co-management of TB and HIV, and the treatment of HIV infection, is complicated by drug interactions, particularly between rifampicin and the NNRTI and PI classes of ARVs. These drugs have similar routes of metabolism and co-administration may result in sub-therapeutic drug levels.

See the Government of the Republic of Zambia “Adult and Adolescent Antiretroviral Therapy Protocols, 2010” for information on the treatment of TB and HIV.

### **Treatment choices for ALHIV who develop TB before ART**

Choice of first-line ARV regimens in ALHIV receiving rifampicin-containing TB treatment

- Pre-pubertal adolescents: 2 NRTIs + EFV
- Post-pubertal adolescents: TDF/FTC or 3TC + EFV. If renal insufficiency ABC + 3TC + EFV.

### **ART switching for ALHIV who develop TB while on first-line ART**

- ART should continue in ALHIV already on a first-line ARV regimen who are subsequently diagnosed with TB. However, the ARV regimen should be reviewed and may need adjustment to ensure optimal treatment of both TB and HIV and to decrease the potential for toxicities and drug-drug interactions.
- In ALHIV on a standard NNRTI-based first-line regimen who develops TB, make adjustments to ART regimens as follows:
  - Pre-pubescent ALHIV: if on a regimen of 2 NRTI + NVP: change NVP with EFV. If on a PI regimen, consult expert for guidance.
  - Post-pubescent ALHIV: if on a regimen that includes NVP, substitute NVP with EFV and continue ART. NOTE: Where TB is being considered as a sign of treatment failure of the first-line regimen, switching to a second-line regimen should be considered if the adolescent has taken ART for more than 24 weeks, has initially responded to it, and has not responded to anti-TB treatment. Consult an HIV expert for the construction of a second-line regimen.



#### **Trainer Instructions**

Slides 75-79

**Step 14:** Ask participants if they have ever heard of the “5 A’s.” Remind participants that the 5 “A’s” are part of the IMAI approach to chronic care.

Review each of the 5 “A’s” with participants and ensure an understanding of each. Tell participants that they will be using the 5 “A’s” to work through case studies in this module, and throughout the training.



### Make These Points

- The 5 “A’s” are a principle of chronic care, developed by WHO and included in the IMAI package of materials.
- The 5 “A’s” include: ASSESS, ADVISE, AGREE, ASSIST, and ARRANGE.
- Healthcare workers can use the 5 “A’s” when providing clinical and psychosocial care and support to adolescent clients (and caregivers).

## Using the 5 “A’s” in Consultations with Adolescent Clients

The 5 “A’s” are part of the WHO IMAI guidelines on working with clients (including adolescents) with chronic conditions, including HIV. Healthcare workers can use the 5 “A’s” when providing clinical and psychosocial care and support to clients.

**Table 3.9: Using the 5 “A’s” during clinical visits with adolescents**

The 5 “A’s”	More Information	What the Healthcare Worker Might Say
<b>ASSESS</b>	<ul style="list-style-type: none"> <li>• Assess the client’s goals for the visit</li> <li>• Asses the client’s clinical status, classify/identify relevant treatments and/or advise and counsel</li> <li>• Assess risk factors</li> <li>• Assess the client’s (caregiver’s) knowledge, beliefs, concerns, and behaviours</li> <li>• Assess the client’s understanding of the care and treatment plan</li> <li>• Assess adherence to care and treatment (see Module 8)</li> <li>• Acknowledge and praise the client’s efforts</li> </ul>	<ul style="list-style-type: none"> <li>• <i>What would you like to address today?</i></li> <li>• <i>What can you tell me about _____?</i></li> <li>• <i>Tell me about a typical day and how you deal with _____?</i></li> <li>• <i>Have you ever tried to _____? What was that like for you?</i></li> <li>• <i>To make sure we have the same understanding, can you tell me about your care and treatment plan in your own words?</i></li> <li>• <i>Many people have challenges taking their medicines regularly. How has this been for you?</i></li> </ul>
<b>ADVISE</b>	<ul style="list-style-type: none"> <li>• Use neutral and non-judgemental language</li> <li>• Correct any inaccurate knowledge and complete gaps in the client’s understanding</li> <li>• Counsel on risk reduction</li> <li>• Repeat any key information that is needed</li> <li>• Reinforce what the client needs to know to manage his or her care and treatment (for example, recognising side effects, adherence tips, problem-solving skills, when to come to the clinic, how to monitor one’s own care, where to get support in the community, etc.)</li> </ul>	<ul style="list-style-type: none"> <li>• <i>I have some information about _____ that I’d like to share with you.</i></li> <li>• <i>Let’s talk about your risk _____. What do you think about reducing this risk by _____.</i></li> <li>• <i>What can I explain better?</i></li> <li>• <i>What questions do you have about _____?</i></li> </ul>

<b>AGREE</b>	<ul style="list-style-type: none"> <li>Negotiate WITH the client about the care and treatment plan, including any changes</li> <li>Plan when the client will return</li> </ul>	<ul style="list-style-type: none"> <li><i>We have talked about a lot today, but I think we've agreed that _____. Is that correct?</i></li> <li><i>Let's talk about when you will return to the clinic for _____.</i></li> </ul>
<b>ASSIST</b>	<ul style="list-style-type: none"> <li>Provide take-away information on the plan, including any changes</li> <li>Provide psychosocial support, as needed</li> <li>Provide referrals, as needed (support groups, peer education, etc.)</li> <li>Address any problems or challenges the client is facing</li> <li>Help the client come up with solutions and strategies that work for him/her</li> </ul>	<ul style="list-style-type: none"> <li><i>Can you tell me more about any challenges you've faced with _____ (for example, taking your medicines regularly, seeking support, practising safer sex)?</i></li> <li><i>How do you think we can solve this problem/challenge?</i></li> <li><i>What questions can I answer about _____?</i></li> <li><i>I want to make sure I explained things well — can you tell me in your own words about _____?</i></li> </ul>
<b>ARRANGE</b>	<ul style="list-style-type: none"> <li>Arrange a follow-up appointment</li> <li>Arrange for attendance in support groups or group education sessions, etc.</li> <li>Record what happened during the visit</li> </ul>	<ul style="list-style-type: none"> <li><i>I would like to see you again in _____ for _____. It's important that you come for this visit, or let us know if you need to reschedule.</i></li> <li><i>What day/time would work for you?</i></li> </ul>

Sources:

WHO. 2004. *General Principles of Good Chronic Care: IMAI. Guidelines for First-level Facility Health Workers.*

WHO. 2010. *IMAI One-day orientation on adolescents living with HIV, 2010.*



### Trainer Instructions

Slides 80-81

**Step 15:** Lead participants through Exercise 1, which will give an opportunity to apply their knowledge of adolescent clinical care to specific case studies.

### Exercise 1: The Adolescent Package of Care: Case studies in small groups and large group discussion

<b>Purpose</b>	<ul style="list-style-type: none"> <li>To review clinical care and treatment of ALHIV according to national guidelines</li> </ul>
<b>Duration</b>	60 minutes
<b>Advance Preparation</b>	<ul style="list-style-type: none"> <li>Review the case studies and suggested answers before the training</li> </ul>
<b>Introduction</b>	We will now break into small groups to work through case studies and apply our clinical care skills for adolescents living with HIV. Remember to use the 5 “A’s” as you discuss your case, keeping in mind the likely needs and challenges of the adolescent client.
<b>Activities</b>	<p><b>Case Studies in Small Groups</b></p> <ol style="list-style-type: none"> <li>Break participants into 4 small, multidisciplinary groups.</li> <li>Ask each group to assign a facilitator and a</li> </ol>

	<p>notetaker. Give each small group flip chart paper and markers.</p> <ol style="list-style-type: none"> <li>3. The notetaker should write “Assess”, “Advise”, “Agree”, “Assist”, and “Arrange” along the left margin of the flip chart paper.</li> <li>4. Refer participants to the case studies written in the Participant Manual. Assign one case study to each small group. Small groups can move on to other case studies if they have time.</li> </ol> <p>Give the small groups about 20 minutes to read and come up with answers to their case study, noting on the flip chart page:</p> <ul style="list-style-type: none"> <li>• Assess: key points inferred from the assessment (participants may have to make inferences from the case study)</li> <li>• Advise: how the client should be advised</li> <li>• Agree: key points that should be negotiated with the client</li> <li>• Assist: how the client should be assisted</li> <li>• Arrange: what services or follow-up appointments need to be arranged and what should be recorded in the notes.</li> </ul> <p>Remind participants to refer to Table 3.9: Using the 5 “A’s” during clinical visits with adolescents” to guide their case study discussions.</p> <p><b>Report Back and Large Group Discussion</b></p> <ol style="list-style-type: none"> <li>5. Bring the large group back together and ask each small group to briefly (5–7 minutes each) present their case study and key points of their discussion.</li> <li>6. Allow time for the large group to comment on and contribute to the case studies. Make any additions or corrections as needed.</li> <li>7. (optional) Be sure to engage the adolescent co-trainer in the small group discussions, as well as the large group presentation of the case studies. He or she should be encouraged to reflect on personal experiences and contribute to the discussions, in particular any adherence or psychosocial issues that participants may have left out.</li> </ol>
<b>Debriefing</b>	<p>A thorough clinical assessment focusing on clinical, laboratory, social, developmental, growth and emotional factors is important at every visit. HIV-related care must be family centered, as often the key to resolving a client’s problems is in working with caregivers or community. Additionally, ensure that the care provided to a client is multidisciplinary, each</p>

	member of the care team knows and understands a different aspect of each client, when these perspectives are shared, a well informed care plan can be developed.
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### **Exercise 1: The Adolescent Package of Care: Case studies in small groups and large group discussion**

**Case Study 1:** Mehluli is a 17 year old adolescent who became infected with HIV 2 years ago. Mehluli had been attending clinic regularly until he went away to attend college. When he attended clinic — up until 6 months ago — he was taking his ART regularly and doing well in school. He’s now been at college for 6 months but has returned for the holidays. During his holiday break he dropped by the clinic. It seems that at college he has become involved in a new church where he was told to stop taking medicine because God will heal. Mehluli states that he feels well and thinks the decision was the right one. How will you proceed with Mehluli?

#### **Key point for trainers: Mehluli**

- Try not to alienate Mehluli; the worst case scenario would be his completing dropping out of care. Spend time listening to him, his reasons for joining the church and for agreeing with their perspective on medication (this is the “Assess” part of the 5 “A’s”). Do not judge.
- Inform him of the dangers of stopping ART: risk of resistance and decline in health.
- Discuss with Mehluli the advantages of ART. Let him know that he might feel fine, but over the long term he will most certainly see a decline in health status if he does not take his ART. Let him know that when he is ready to re-start ART that you will be here.
- Ask Mehluli if he is sexually active, discuss safer sex and emphasize the importance of disclosure and condom use.
- Discuss with Mehluli the possibility that he, as a compromise, at least continue to take CTX, even if he stops taking ART. Give him a reason to continue to attend clinic on his holidays — it could be for continuing social services or CTX refills.
- If Mehluli gives permission, then reach out to the leaders of the church he is attending, suggest that you meet with them to discuss the importance of modern medicine and to encourage tolerance of those who need to take drugs to live.
- As long as you have Mehluli in the clinic (even though he only dropped by to say hello), try to convince him to stay so that you can provide him with the routine follow-up care (as per the follow-up clinical assessment list that starts on page 13).

**Case Study 2:** Katai, who is 16 and acquired HIV through MTCT, went to live with relatives when her parents died three years ago. She has never felt completely welcome at her aunt and uncle’s home. Although they do

support her to take her ART regularly, she just has never felt “loved”. She feels that her uncle is unsupportive of her in general, he makes her do more chores than his own children are required to do, and he never gives her enough money to buy what she needs. Over the past year or so she has been going to bars and finding the company she craves by having sex with any man she can pick up. How will you proceed with Katai?

#### **Key point for trainers: Katai**

- Stress with Katai that she is responsible for ensuring that when she does have sex that it is safer sex. Discuss either abstaining from alcohol or drinking moderately, as alcohol can lead to unsafe sex. Counsel her on how to negotiate condoms. If you need to, stress to her that she could actually go to jail, as it is against the law to have sex with the intention of infecting them with HIV.
- If she is unwilling just yet to give up casual sex, consider negotiating a plan that is a compromise, but still reduces harm (“harm reduction”). For example, ensures that her partners use condoms every time. In terms of harm reduction, maybe as a compromise you can suggest that Katai reduce the number of partners from several per week to just one (or two). Although this may sound as if you are giving her permission to engage in casual sex, it is a compromise, a means to an end (the end goal is for her to find one monogamous partner with whom she shares a meaningful relationship). Even with partner reduction it is important that she still insists that her partner use a condom.
- Ensure Katai is using contraception. Ideally she should be using dual protection: condoms as well as another form of family planning such as the pill.
- Discuss the importance of disclosure of HIV status to her partners.
- Assess Katai’s cognitive development, as cognitive delays can interfere with the establishment of healthy relationships. If there are delays, provide support.
- Ensure Katai is on ART, even if her CD4 is higher than 350, as she qualifies as she would be considered the HIV-positive partner in a discordant relationship.
- If she is on ART, ensure her adherence is excellent. Those with high CD4 count are less infectious.
- Consider family counselling with her aunt and uncle (or just her aunt, if that is more comfortable for Katai).

**Case Study 3:** Sonkwe is a 12 year old who was infected with HIV perinatally. Although Sonkwe has had his ups and down, in terms of health, as of the past year there has been a definite decline. Sonkwe is small for his age, and has not grown in the past year. He is recently recovered from a WHO Stage 2 illness. During the counselling session with Sonkwe, he stated that his caregivers expect *him* to remember to take his ARVs every day. When he forgets, they do not think to remind him. His

caregivers feel that, as he is now 12 that he is old enough to take responsibility for his own health. How will you proceed with Sonkwe?

**Key point for trainers: Sonkwe**

- At this point we cannot tell if Sonkwe is failing his ARV regimen or if his poor health is due to poor adherence. First, ask about his adherence. If his adherence has been excellent, then refer this case to the multidisciplinary team/HIV specialist to rule out treatment failure. If his adherence has been less than excellent — which we're quite sure is the case — then provide adherence counselling to help him achieve excellent adherence.
- It seems that Sonkwe is just not mature enough to take full responsibility for taking his ART every day, but discuss this observation with him and see what he says. If he agrees, discuss this with his caregiver and recommend that the caregiver take responsibility for ensuring that Sonkwe takes his ARVs every day exactly as prescribed. This will take the pressure off of Sonkwe. But work with his caregivers to ensure that they have the tools they need to remind him to take his medications every day and to ensure that he really does take them.
- As Sonkwe is pre-pubescent, use his current weight and re-calculate his CTX and ARV dosages to make sure dosages are correct.
- Review his most recent CD4 cell count, in light of the fact that he has recently has a Stage 2 illness. Consider requesting another CD4 cell count, particularly if the most recent is more than 3 months old.
- Discuss adherence to CTX as well as any medication prescribed for his recent illness.
- As he is losing weight, conduct a nutrition assessment and advise accordingly.

**Case Study 4:** Trina, who is 17, was diagnosed with HIV 1 year ago. Trina is quite healthy, her CD4 cell count was 500 and at the last visit she was a clinical stage 1. The only reason she was tested last year is because she heard through a girl friend that her old boyfriend was rumoured to have HIV. Today Trina looks thin and tired — much different than she looked the last time you saw her just 6 months ago. When she comes into the exam room you realise that she's been coughing as well. How will you proceed with Trina?

**Key point for trainers: Trina**

- **Assess:** A key issue from the healthcare worker's perspective is the apparent decline in Trina's health. Ensure the physical exam and interim history are thorough. Enquire about pregnancy and STIs.
- As she is experiencing weight loss and coughing, ensure Trina is screened for TB, even if she was put on IPT at the last visit.

- Request a CD4 cell count. If she does have TB, she will be eligible for ART, based on clinical criteria.
- Keep in mind that if she does have TB, she will be started on TB medications first, and then, when stabilised started on ART. Nonetheless, if you think she will be eligible for ART using either immunological (CD4 cell count) or clinical (for example, if she does appear to have TB) criteria, initiate adherence preparation (which takes 3 visits, see Module 8).
- Find out what Trina defines as her key issues for today's visit. Undertake a thorough psychosocial assessment. Keep in mind that Trina's underlying issue may be psychosocial, and not physical (for example, a recent break up with a boyfriend, argument with her parents, failing grades at school, etc).
- If Trina is currently sexually active, ensure she is on contraception and is empowered to negotiate safer sex.
- Advise, agree, and assist Trina according to the findings from the physical exam and psychosocial assessment.



### Trainer Instructions

**Step 16:** Allow 5 minutes for questions and answers on this session.



### Trainer Instructions

Slides 82-84

**Step 17:** Ask participants what they think the key points of the module are. What information will they take away from this module?

Summarise the key points of the module using participant feedback and the content below.

**Step 18:** Provide copies of “Guidelines for Antiretroviral Therapy for HIV in Infants and Children in Zambia” and “Adult and Adolescent Antiretroviral Therapy Protocols, 2010”, if possible. Refer participants to the national training courses in these areas for more information.

**Step 19:** Ask if there are any questions or clarifications.



### **Module 3: Key Points**

- There are 2 specific groups of ALHIV (defined by the mode of HIV transmission), whose histories, experiences and needs may differ significantly — adolescents who acquired HIV perinatally, and those that acquired HIV later in childhood or adolescence.
- While the components of the adolescent package of HIV care closely resemble those of the adult package of care, how they are delivered can have an impact on uptake and success. To be effective, the adolescent package of care must ensure:
  - Integration of services
  - That services are age and developmentally appropriate
  - That they are responsive to the needs of both perinatally infected adolescents, as well as those infected later in childhood or adolescence
  - That there is an emphasis on both care and treatment, and retaining adolescents not eligible for ART in care
  - That services are family-centred
- Key components of comprehensive care for ALHIV include the following:
  - Assess growth, nutrition, and development
  - Conduct physical examination and confirm stage of HIV disease
  - Prevent, diagnose and treat OIs and other concomitant conditions, including tuberculosis
  - If eligible, provide ART (if  $CD4 \leq 350$  or stage 3 or 4) and CTX (if  $CD4 < 350$  or stage 2, 3 or 4) as well as adherence monitoring and support
  - Provide the client and his or her family with psychosocial assessment, counselling, education and support, including for disclosure; provide referral for follow up
  - Discuss findings, advise and guide

## Appendix 3A: Clinical and Laboratory Monitoring for ALHIV

Laboratory tests for diagnosis and monitoring	Baseline (at entry into care)	At initiation of first- or second-line ART regimen	Every 6 months	As required or symptom directed
HIV Antibody testing	✓			
Haemoglobin <sup>a</sup> (and white cell count, if available) or FBC	✓	✓		✓
LFT <sup>c</sup> and RFT	✓			✓
CD4 cell count <sup>d</sup>	✓	✓	✓	✓
Creatinine Clearance <sup>e</sup>	✓	✓		✓
ALT and/or AST <sup>f</sup>	✓			
Urinalysis	✓			
Pregnancy testing in adolescent girls <sup>gh</sup>		✓		✓
Full chemistry (including, but not restricted to, liver enzymes, renal function, glucose, lipids, amylase, lipase and serum electrolytes) <sup>i</sup>		✓		✓
HIV VL measurement <sup>jk</sup>				✓
Hepatitis B and C status (where available)	✓			
RPR	✓			✓
OI screening (where possible)	✓	✓	✓	✓
Sexually active females: PAP smear (if unavailable, then visualisation with acetic acid screening) or refer to next level of care for PAP smear <sup>l</sup>	✓			✓
If available, chemistry panel to include glucose, cholesterol, triglycerides	✓			

- a. Monitor haemoglobin at week 4 and 12 after initiation of ART if AZT is used.
- b. FBC can be repeated at initiation of ART if last FBC was done at least 3 months prior. If FBC is not available at baseline, conduct haemoglobin measurement.
- c. Liver function tests (LFT i.e. liver enzymes) are recommended during the first few months of treatment in children receiving NVP who have signs of hepatitis or hepatotoxicity, who are co-infected with hepatitis viruses, or who are on hepatotoxic medications. Based on data in adults on ART, routine monitoring of LFTs is unlikely to be cost-effective.
- d. HIV-infected children not yet eligible for ART should be monitored with CD4 count every six months. For infants and children who develop new or recurrent WHO stage 2 or 3 events, or whose CD4 count approaches threshold values, the frequency of CD4 measurement can be increased. %CD4+ is preferred in children <5 years of age.

- e. Repeat creatinine clearance 12 weeks, 6 months and then yearly after initiating ART. See the Zambia “Adult and Adolescent Antiretroviral Therapy Protocols, 2010” for additional information.
- f. Conduct ALT and/or AST in patients initiated on NVP-containing regimen or those testing HBsAg positive. Monitor closely in the first 12 weeks of initiating a NVP-containing regimen.
- g. Pregnancy testing needed for sexually active adolescent girls prior to initiating a regimen containing EFV.
- h. For pregnant adolescent girls, provide prophylaxis or combination ART to those who are in need of it for their own health and/or to prevent vertical transmission. (See WHO PMTCT Guidelines, 2010) [102]
- i. Routine monitoring (every six months) of full chemistry, particularly lipid levels, liver enzymes and renal function, should be considered for infants and children on second-line drugs and LFTs for those on NVP.
- j. At present, VL measurement is not a prerequisite for initiation or regular monitoring of ART in resource-limited settings. VL can be used to diagnose HIV infection, and to confirm clinical or immunological failure prior to switching treatment regimen.
- k. If possible VL should be assessed in infants on NNRTI-based regimens who are known to have been exposed to NNRTIs intrapartum or through breastfeeding every 6 months.
- l. Repeat PAP or visual screen at 6 months and if normal, every 12 months

## Appendix 3B: HEADSS Interview Questions

✓	Topic and key points
	<b>1. Home and environment</b>
	<ul style="list-style-type: none"> <li>• Where do you live, and who lives there with you?</li> </ul>
	<ul style="list-style-type: none"> <li>• How many brothers and sisters do you have and what are their ages? Are your brothers and sisters healthy?</li> </ul>
	<ul style="list-style-type: none"> <li>• Are there any new people living in your home?</li> </ul>
	<ul style="list-style-type: none"> <li>• What are the rules like at home?</li> </ul>
	<ul style="list-style-type: none"> <li>• How do you get along with your parents, your siblings? What kinds of things do you and your family argue about the most? What happens in the house when there is a disagreement?</li> </ul>
	<ul style="list-style-type: none"> <li>• Is there anything you would like to change about your family?</li> </ul>
	<b>2. Education and employment</b>
	<ul style="list-style-type: none"> <li>• Are you in school? What are you good at in school? What is hard for you? What grades do you get?</li> </ul>
	<ul style="list-style-type: none"> <li>• Which school do you go to? Any recent changes in schools?</li> </ul>
	<ul style="list-style-type: none"> <li>• What do you like best and least about school? Favourite subjects? Worst subjects?</li> </ul>
	<ul style="list-style-type: none"> <li>• What were your most recent grades? Are these the same or different from the past?</li> </ul>
	<ul style="list-style-type: none"> <li>• How many hours of homework do you do daily?</li> </ul>
	<ul style="list-style-type: none"> <li>• How much school did you miss last/this year?</li> </ul>
	<ul style="list-style-type: none"> <li>• What do you want to do when you finish school? Any future plans/goals?</li> </ul>
	<ul style="list-style-type: none"> <li>• Do you work now? How much? Have you worked in the past?</li> </ul>
	<ul style="list-style-type: none"> <li>• How do you get along with teachers, employers?</li> </ul>
	<b>3. Activities</b>
	<ul style="list-style-type: none"> <li>• What do you do for fun? What things do you do with friends? What do you do with your free time?</li> </ul>
	<ul style="list-style-type: none"> <li>• Are most of your friends from school or somewhere else? Are they the same age as you?</li> </ul>
	<ul style="list-style-type: none"> <li>• Do you hang out with mainly people of your same sex or a mixed crowd?</li> </ul>
	<ul style="list-style-type: none"> <li>• Do you have one best friend or a few friends? Do you have a lot of friends?</li> </ul>
	<ul style="list-style-type: none"> <li>• Do you spend time with your family? What do you do with your family?</li> </ul>
	<ul style="list-style-type: none"> <li>• Do you see your friends at school and on weekends, too? Are there a lot of parties?</li> </ul>
	<ul style="list-style-type: none"> <li>• Do you do any regular sport or exercise? Hobbies or interests?</li> </ul>
	<ul style="list-style-type: none"> <li>• Do you have a religious affiliation, belong to a church, or practice some kind of spiritual belief?</li> </ul>
	<ul style="list-style-type: none"> <li>• Do you read for fun? What do you read?</li> </ul>
	<ul style="list-style-type: none"> <li>• What is your favourite music?</li> </ul>

<b>4. Drugs</b>	
	<ul style="list-style-type: none"> <li>• Many young people experiment with drugs, alcohol, or cigarettes. Have you or your friends ever tried them? What have you tried?</li> </ul>
	<ul style="list-style-type: none"> <li>• When you go out with your friends or to party, do most of the people that you hang out with drink or smoke? Do you? How much and how often?</li> </ul>
	<ul style="list-style-type: none"> <li>• Do any of your family members drink, smoke or use other drugs? If so, how do you feel about this — is it a problem for you?</li> </ul>
	<ul style="list-style-type: none"> <li>• Have you or your friends ever tried any other drugs? Specifically, what? Have you ever used a needle?</li> </ul>
	<ul style="list-style-type: none"> <li>• Do you regularly use other drugs? How much and how often?</li> </ul>
	<ul style="list-style-type: none"> <li>• Have you ever been in a car accident or in trouble with the law, and were any of these related to drinking or drugs?</li> </ul>
	<ul style="list-style-type: none"> <li>• How do you pay for your cigarettes, alcohol or drugs?</li> </ul>
<b>5. Sexuality</b>	
	<ul style="list-style-type: none"> <li>• Are you involved in a relationship? Have you been involved in a relationship? How was that experience for you?</li> </ul>
	<ul style="list-style-type: none"> <li>• How would you describe your feeling towards boys or girls?</li> </ul>
	<ul style="list-style-type: none"> <li>• How do you see yourself in terms of sexual preference, i.e. gay, straight, or bisexual?</li> </ul>
	<ul style="list-style-type: none"> <li>• Have you had sex? Was it a good experience? Are you comfortable with sexual activity? Number of partners?</li> </ul>
	<ul style="list-style-type: none"> <li>• Using contraception? Type and how often (10, 50, or 70% of the time).</li> </ul>
	<ul style="list-style-type: none"> <li>• Have you ever been pregnant or had an abortion?</li> </ul>
	<ul style="list-style-type: none"> <li>• Have you ever had a discharge or sore that you are concerned about? Knowledge about STDs and prevention?</li> </ul>
	<ul style="list-style-type: none"> <li>• Have you ever had a pap smear?</li> </ul>
	<ul style="list-style-type: none"> <li>• Have you had an experience in the past where someone did something to you that you did not feel comfortable with or that made you feel disrespected?</li> </ul>
	<ul style="list-style-type: none"> <li>• If someone abused you, who would you talk to about this? How do you think you would react to this?</li> </ul>
	<ul style="list-style-type: none"> <li>• For females: Ask about menarche, last menstrual period (LMP), and menstrual cycles. Also inquire about breast self examination (BSE) practices.</li> </ul>
	<ul style="list-style-type: none"> <li>• For males: Ask about testicular self-examination (TSE) practices.</li> </ul>
<b>6. Suicide/depression</b>	
	<ul style="list-style-type: none"> <li>• See “Appendix 6C: Screening Tool for Suicide”</li> </ul>

Adapted from: “H.E.A.D.S.S. — A Psychosocial Interview For Adolescents”  
[http://search.phsa.ca/cgi-bin/MsmGo.exe?grab\\_id=0&page\\_id=8144&query=HEADSS](http://search.phsa.ca/cgi-bin/MsmGo.exe?grab_id=0&page_id=8144&query=HEADSS)

## Appendix 3C: WHO Staging for Children with Established HIV Infection

Use this clinical staging for adolescents younger than 15 years of age.

<b>Clinical Stages</b>	
<b>Clinical Stage 1</b>	
<ul style="list-style-type: none"> <li>Asymptomatic</li> </ul>	<ul style="list-style-type: none"> <li>Persistent generalised lymphadenopathy</li> </ul>
<b>Clinical Stage 2</b>	
<ul style="list-style-type: none"> <li>Unexplained persistent hepatosplenomegaly</li> <li>Papular pruritic eruptions</li> <li>Extensive wart virus infection</li> <li>Extensive molluscum contagiosum</li> <li>Unexplained persistent parotid enlargement</li> </ul>	<ul style="list-style-type: none"> <li>Recurrent oral ulcerations</li> <li>Lineal gingival erythema</li> <li>Herpes zoster</li> <li>Recurrent or chronic upper respiratory tract infection (otitis media, otorrhea, sinusitis, tonsillitis)</li> <li>Fungal nail infections</li> </ul>
<b>Clinical Stage 3</b>	
<ul style="list-style-type: none"> <li>Unexplained moderate malnutrition not adequately responding to standard therapy</li> <li>Unexplained persistent diarrhoea (14 days or more)</li> <li>Unexplained persistent fever (above 37.5°C intermittent or constant, for longer than 1 month)</li> <li>Persistent oral Candida (outside first 6–8 weeks of life)</li> <li>Acute necrotising ulcerative gingivitis/periodontitis</li> </ul>	<ul style="list-style-type: none"> <li>Oral hairy leukoplakia</li> <li>Lymph node TB</li> <li>Pulmonary TB</li> <li>Severe recurrent presumed bacterial pneumonia</li> <li>Symptomatic lymphoid interstitial pneumonitis</li> <li>Chronic HIV-associated lung disease including bronchiectasis</li> <li>Unexplained anaemia (&lt;8g/dl), neutropenia (&lt;05 x 10<sup>9</sup>) or chronic thrombocytopenia (&lt;50 x 10<sup>9</sup>/l)</li> </ul>
<b>Clinical Stage 4</b>	
<ul style="list-style-type: none"> <li>Unexplained severe wasting, stunting or severe malnutrition not responding to standard therapy</li> <li>Pneumocystis pneumonia</li> <li>Recurrent severe bacterial infections (for example, empyema, pyomyositis, bone or joint infection, meningitis, but excluding pneumonia)</li> <li>Chronic herpes simplex infection; (orolabial or cutaneous &gt; 1 month's duration or visceral at any site)</li> <li>Extra pulmonary tuberculosis</li> <li>Kaposi sarcoma</li> <li>Esophageal candidiasis (or Candida of trachea, bronchi or lungs)</li> <li>Central nervous system toxoplasmosis (outside the neonatal period)</li> <li>HIV encephalopathy</li> <li>Chronic Isosporiasis</li> </ul>	<ul style="list-style-type: none"> <li>Cytomegalovirus (CMV) infection; retinitis or CMV infection affecting another organ, with onset at age &gt;1 month.</li> <li>Extra pulmonary cryptococcosis including meningitis</li> <li>Disseminated endemic mycosis (extra pulmonary histoplasmosis, coccidiomycosis, penicilliosis)</li> <li>Chronic Cryptosporidiosis</li> <li>Disseminated non-tuberculous mycobacteria infection</li> <li>Acquired HIV-associated rectal fistula</li> <li>Cerebral or B cell non-Hodgkin lymphoma               <ul style="list-style-type: none"> <li>Progressive multifocal leukoencephalopathy</li> <li>HIV-associated cardiomyopathy or HIV-associated nephropathy</li> </ul> </li> </ul>

Adapted from: Republic of Zambia Ministry of Health. (2007): *Zambian Guidelines for Antiretroviral Therapy of HIV Infection in Infants and Children*

## Appendix 3D: WHO Clinical Staging of HIV Disease in Adults and Adolescents

Use this clinical staging for adolescents age 15 years or older.

<b>Clinical Stages</b>	
<b>Clinical Stage 1</b>	
<ul style="list-style-type: none"> <li>Asymptomatic</li> </ul>	<ul style="list-style-type: none"> <li>Persistent generalised lymphadenopathy</li> </ul>
<b>Clinical Stage 2</b>	
<ul style="list-style-type: none"> <li>Moderate unexplained<sup>1</sup> weight loss (under 10% of presumed or measured body weight)<sup>2</sup></li> <li>Recurrent respiratory tract infections (sinusitis, tonsillitis, otitis media, pharyngitis)</li> </ul>	<ul style="list-style-type: none"> <li>Herpes zoster</li> <li>Angular cheilitis</li> <li>Recurrent oral ulceration</li> <li>Papular pruritic eruptions</li> <li>Seborrhoeic dermatitis</li> <li>Fungal nail infections</li> </ul>
<b>Clinical Stage 3</b>	
<ul style="list-style-type: none"> <li>Unexplained<sup>1</sup> severe weight loss (over 10% of presumed or measured body weight)<sup>2</sup></li> <li>Unexplained<sup>1</sup> chronic Candidiasis for longer than one month</li> <li>Unexplained persistent fever (intermittent or constant for longer than one month)</li> <li>Persistent oral Candidiasis</li> <li>Oral hairy leukoplakia</li> </ul>	<ul style="list-style-type: none"> <li>Pulmonary tuberculosis</li> <li>Severe bacterial infections (for example, pneumonia, empyema, pyomyositis, bone or joint infection, meningitis, bacteraemia)</li> <li>Acute necrotising ulcerative stomatitis, gingivitis or periodontitis</li> <li>Unexplained anaemia (below 8 g/dl), neutropenia (below 0.5 x 10<sup>9</sup>/l) and/or chronic thrombocytopenia (below 50 x 10<sup>9</sup> /l)</li> </ul>
<b>Clinical Stage 4</b>	
<ul style="list-style-type: none"> <li>HIV wasting syndrome</li> <li>Pneumocystis Jiroveci pneumonia</li> <li>Recurrent severe bacterial pneumonia</li> <li>Chronic herpes simplex infection (oro-labial, genital or ano-rectal of more than one month's duration or visceral at any site)</li> <li>Oesophageal Candidiasis (or Candidiasis of trachea, bronchi or lungs)</li> <li>Extra pulmonary tuberculosis</li> <li>Kaposi sarcoma</li> <li>Cytomegalovirus infection (retinitis or infection of other organs)</li> <li>Central nervous system toxoplasmosis</li> <li>HIV encephalopathy</li> <li>Extra pulmonary cryptococcosis including meningitis</li> </ul>	<ul style="list-style-type: none"> <li>Disseminated non-tuberculosis mycobacterial infection</li> <li>Progressive multifocal leukoencephalopathy</li> <li>Chronic cryptosporidiosis</li> <li>Chronic isosporiasis</li> <li>Disseminated mycosis (extra pulmonary histoplasmosis, coccidiomycosis)</li> <li>Recurrent septicaemia (including non-typhoidal Salmonella)</li> <li>Lymphoma (cerebral or B cell non-Hodgkin)</li> <li>Invasive cervical carcinoma</li> <li>Atypical disseminated leishmaniasis</li> <li>Symptomatic HIV-associated nephropathy or HIV-associated cardiomyopathy</li> </ul>
<sup>1</sup> Unexplained refers to a condition that is not explained by other conditions. <sup>2</sup> Assessment of body weight among pregnant women needs to consider the expected weight gain of pregnancy.	

Adapted from: WHO. (2006). Revised WHO clinical staging and immunological classification of HIV and case definition of HIV for surveillance.

## Appendix 3E: ARV Dosages for Post-pubertal Adolescents and Adults

Drug	Usual adult dosage	Notes
Efavirenz (EFV)	600 mg once a day Evening dosing on an empty stomach recommended initially to decrease side effects.	Contraindicated in 1st trimester of pregnancy.
Emtricitabine (FTC)	200 mg once a day, With or without food	Can be administered as a co-formulated product with TDF (Truvada) or with TDF and EFV (Atripla).  Adjust if CrCl <50 ml/min.
Lamivudine (3TC)	300 mg once a day	Can cause pancreatitis. Adjust if CrCl <50 ml/min.
Boosted Lopinavir (LPV/r)	400/100 mg twice a day, With or without food	Can cause hyperlipidemia, insulin resistance, pancreatitis, transaminitis, and/or fat redistribution
Nevirapine (NVP)	200 mg twice a day	Two-week lead-in recommended (200 mg once a day), as it reduces risk of rash and hepatotoxicity.  Can cause Stevens Johnson Syndrome, toxic epidermal necrolysis, hepatotoxicity (monitor ALT/AST first 12 weeks), liver failure, and hypersensitivity
Stavudine (d4T)	<ul style="list-style-type: none"> <li>Wt &gt;60 kg: 40 mg twice-daily</li> <li>Wt &lt;60 kg: 30 mg twice-daily</li> </ul> (WHO recommends and data supports 30 mg twice-daily, less toxic and equally effective.)	Contraindicated with AZT due to in vitro and in vivo antagonism.  Can cause peripheral neuropathy, lipoatrophy, hyperlipidemia, pancreatitis, lactic acidosis.  Adjust if CrCl <50 ml/min.
Tenofovir (TDF)	300 mg once a day, With or without food	Avoid TDF based regimen in patients with renal insufficiency (CrCl <50 ml/min).
Zidovudine (AZT)	300 mg twice a day, With or without food (often better tolerated with food)	Avoid AZT in patients with Hb <10 gm/dl (monitor Hb in the first 12 weeks). Can also cause neutropenia, myopathy, and lactic acidosis.  Adjust if CrCl <15 ml/min.

For information on serious, acute, and chronic toxicities, see “Guidelines for Antiretroviral Therapy for HIV in Infants and Children in Zambia” Annex B and Annex C.

## References and Resources

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<sup>1</sup> WHO/UNICEF. 2008. *Global Consultation on Strengthening the Health Sector Response to Care, Support, Treatment and Prevention for Young People Living with HIV*. Geneva, Switzerland: WHO/UNICEF.



# Module 4 Communicating with and Counselling Adolescents



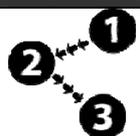
**Total Module Time:** 250 minutes (4 hours, 10 minutes)

## Learning Objectives

**After completing this module, participants will be able to:**

- Discuss ways to establish trust and rapport with adolescent clients.
- Demonstrate effective counselling skills.
- Identify and address common challenges in counselling adolescent clients.

## Methodologies



- Interactive trainer presentation
- Large group discussion
- Brainstorming
- Case studies
- Role play
- Small group work

## Materials Needed



- Slide set for Module 4
- Flip chart and markers
- Tape or Bostik
- Participants should have their Participant Manuals. The Participant Manual contains background technical content and information for the exercises.

## References and Resources



- WHO. 2010. *IMAI One-day orientation on Adolescents Living with HIV*, Facilitator Guide, Geneva, WHO Press.
- WHO/UNICEF. 2008. *Global Consultation on Strengthening the Health Sector Response to Care, Support, Treatment and Prevention for Young People Living with HIV*. Geneva, Switzerland: WHO/UNICEF.
- Republic Of Zambia, Ministry Of Health. 2010. *National Training Package on Paediatric Provider-initiated HIV Testing & Counselling in Zambia*.



**Advance Preparation**



- Read through the entire module and ensure that all trainers are prepared and comfortable with the content and methodologies.
- Review the appendices in this module ahead of time and prepare to incorporate them into the discussion.
- Exercise 2 requires advance preparation. Please review ahead of time.

### **Session 4.1: Establishing Trust and Rapport with Adolescent Clients**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation and large group discussion	10 minutes
Exercise 1: Establishing Rapport and Building Trust: Role play and large group discussion	30 minutes
Questions and answers	5 minutes
<b>Total Session Time</b>	<b>45 minutes</b>

### **Session 4.2: Effective Techniques for Counselling Adolescents**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation and large group discussion	70 minutes
Exercise 2: Practise Listening and Learning Skills: Case studies in small groups and large group discussion	60 minutes
Questions and answers	5 minutes
<b>Total Session Time</b>	<b>135 minutes</b>

### **Session 4.3: Challenges and Solutions to Counselling Adolescent Clients**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation and large group discussion	25 minutes
Exercise 3: Overcoming Communication Challenges: Large group discussion using case studies	30 minutes
Questions and answers	5 minutes
Review of key points	10 minutes
<b>Total Session Time</b>	<b>70 minutes</b>

## Session 4.1      Establishing Trust and Rapport with Adolescent Clients



**Total Session Time:** 45 minutes



### Trainer Instructions

Slides 1-4

- Step 1:** Begin by reviewing the Module 4 learning objectives and the session objective, listed below.
- Step 2:** Ask participants if there are any questions before moving on.

### Session Objective

**After completing this session, participants will be able to:**

- Discuss ways to establish trust and rapport with adolescent clients.



### Trainer Instructions

Slides 5-10

- Step 3:** Explain that establishing trust is the starting point for good communication. In order to encourage adolescent clients to feel comfortable expressing their needs, it is important to understand their mindset and be responsive to what they are feeling. Begin by asking participants the following questions and record responses on a flip chart:
- *What are some general characteristics of adolescence that can influence trust and rapport with a healthcare worker?*
  - *What do you think an ALHIV coming to the clinic might be concerned about?*
- Write the words “TO DO,” “TO AVOID,” and “FEELINGS” on 3 separate pieces of flip chart paper. Ask the following questions to facilitate discussion and record key points under the relevant heading:
- *What are some things a healthcare worker might do to build trust and rapport with an adolescent?*
  - *What are some things that a healthcare worker should avoid?*
  - *What are some typical feelings that an adolescent might experience, which could affect his or her trust and*

*relationship with you as a healthcare worker?*

Debrief by reviewing the tips for good rapport with adolescents in the content below (focus on content that didn't come up during the discussion).

**Step 4:** (optional) Ask the adolescent co-trainer the following questions to encourage his or her input and participation:

- *Do you remember an occasion when a healthcare worker communicated with you in a way that helped build your trust? Please explain.*
- *Do you have an example of an occasion when a healthcare worker communicated in a way that was not helpful or supportive? Please explain.*



### **Make These Points**

- Building trust and rapport with adolescent clients starts with understanding their feelings and mindset. Being able to understand the perspective of the adolescent will enable the healthcare worker to respond appropriately and create a positive and effective service experience.
- Adolescents may have feelings of discomfort, embarrassment, shyness, and uncertainty when communicating with healthcare workers about personal issues (for example, sexuality, wanting to have sex, wanting to have a baby).
- Encouraging trust and rapport with adolescents means demonstrating respect at all times, being non-judgemental, ensuring confidentiality, showing empathy for the adolescent's situation, using age-appropriate language, reassuring them that their feelings are normal, and showing a sincere willingness to help.
- Communication approaches and techniques for building rapport with ALHIV need to be tailored to the needs of the particular individual. What works for one adolescent, will not necessarily work for another.

## **Strategies for Establishing Trust and Rapport with the Adolescent Client<sup>1</sup>**

ALHIV may have any number of personal concerns related to their diagnosis, disclosure of their HIV status, feelings of isolation, and coping with a chronic condition. In order to provide them with support and information, healthcare workers must first establish trust and rapport.

Establishing trust with an adolescent can be difficult because:

- Adolescence is a unique phase of life. The adolescent is going through dramatic biological and emotional changes. Seeking health care may seem challenging because the normal changes of adolescence affect

the young person's self-confidence, relationships, social skills, and general thinking.

- Adolescents may feel fearful, embarrassed, or uncomfortable around healthcare workers. They may be reluctant to disclose personal information for fear of being scolded or mocked, especially if a caregiver is present.
- Most adolescents have concerns about confidentiality, which will impact their willingness to discuss personal issues with the healthcare worker. **Healthcare workers should always reassure adolescents, during one-to-one counselling sessions, that what is discussed in the counselling session will remain confidential.** Clarify what this means: although the healthcare worker may have to share information with other healthcare workers — if it is critical in making decisions about the client's care — discussions with clients are never shared with anyone outside of the multidisciplinary team. These discussions are not even shared with caregivers or partners, unless the client gives explicit permission.
- Adolescents who are in same-sex relationships may feel that they will face discrimination if they reveal their relationship to others. Instead, they are likely to choose to lie about their relationships or the gender of their current partner, making it impossible for healthcare workers to tailor prevention strategies to their situations.

**When face-to-face with a healthcare worker (or an adult staff member) many adolescents feel:**

- *Shy* about being in a clinic and about needing to discuss personal matters.
- *Embarrassed* that they are seeking assistance on a taboo topic (HIV, sex, sexuality, wanting to have sex, wanting to have a baby).
- *Worried* that someone will see them and tell their parents.
- *Inadequate* at describing their concern and ill-informed about health matters in general.
- *Anxious* that they have a serious condition that has significant consequences .
- *Afraid* that they might die.
- *Intimidated* by the medical facility and/or the many “authority figures” in the facility.
- *Defensive* about being the subject of the discussion or because they were referred against their will.
- *Resistant* to receiving help or engaging in care and treatment because of rebelliousness, a fear of the unknown, or another reason.
- *Unsure* about how to ask for help around living with a chronic condition.

**The following are tips for building rapport with adolescents:**

- Treat everyone equally and with respect.
- Be genuinely open to an adolescent's questions or need for information.
- Do not use judgemental words or body language. Do not talk down to an adolescent by scolding, shouting, blaming, or getting angry.

- Use words and language that an adolescent can understand, and are appropriate to their age and developmental stage. Use educational materials, like flip charts or pictures, to explain complicated information.
- Do not be critical of an adolescent’s appearance or behaviour.
- If sensitive issues are being discussed, help ensure that conversations are not seen or overheard by others.
- Do not threaten to break an adolescent’s confidentiality “for their own good.”
- Adolescents may be reluctant to disclose personal information if their parents or caregivers are present. Healthcare workers should stress that information entrusted with them will not be shared, unless the client gives permission.
- Allow enough time for the adolescent client to become comfortable enough during the visit to ask questions and express concerns.
- Show an understanding of and empathize with the client’s situation and concerns. Try and put yourself “in the adolescent’s shoes.”
- Understand that they might be uncomfortable; be reassuring when responding to them. Explain that you “*are here to help.*”
- Reassure adolescents that their feelings and experiences are normal.
- Be honest and admit when you do not know the answer to a question.



### Trainer Instructions

Slides 11-17

**Step 5:** Lead participants through Exercise 1, which gives an opportunity to discuss and practise some skills required for building rapport and trust with an adolescent client.

### Exercise 1: Establishing Rapport and Building Trust: Role play and large group discussion

<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To practise establishing rapport and building trust with adolescent clients</li> </ul>
<b>Duration</b>	30 minutes
<b>Advance Preparation</b>	<ul style="list-style-type: none"> <li>• None for this exercise</li> </ul>
<b>Introduction</b>	It is important to remember that adolescents may feel anxious, uncomfortable or uncertain when speaking to healthcare workers, especially when disclosing personal information. Therefore, as healthcare workers, we must be self-aware about our own behaviour and be able to identify what we should DO and what we should AVOID to facilitate the establishment of trust with adolescent clients. This exercise will give us an opportunity to apply some trust-building strategies and discuss options for how to respond to adolescent clients.
<b>Activities</b>	<b>Large group discussion, with role play</b> 1. Ask participants to review the case studies in their

	<p>Participant Manual.</p> <ol style="list-style-type: none"> <li>2. Ask 2 participants to volunteer to role play the 1<sup>st</sup> case study in front of the large group. One participant will be the “healthcare worker” and the other the “client.” Ask the “healthcare worker” to incorporate into his or her counselling style some of the tips and strategies discussed in Session 4.1.</li> <li>3. Give the “healthcare worker” and “client” about 5–8 minutes to conduct their role play.</li> <li>4. Upon completion of the role play, facilitate a discussion by asking the following questions: <ul style="list-style-type: none"> <li>• <i>What do you think the adolescent was thinking/experiencing in this situation? What do you think he or she was concerned with?</i></li> <li>• <i>How did the healthcare worker try to build rapport and trust with the client?</i></li> <li>• <i>What was done well?</i></li> <li>• <i>What would you do differently?</i></li> </ul> </li> <li>5. If there is sufficient time, invite two other volunteers to role play the 2<sup>nd</sup> case study in front of the large group, following steps 1–4, above. If there is insufficient time, ask a participant to read the 2<sup>nd</sup> case study; discuss in the large group the healthcare worker’s potential responses to the client. Ask the following questions to encourage discussion: <ul style="list-style-type: none"> <li>• <i>How could the healthcare worker build rapport and trust with the client in this situation? What should the healthcare worker say and do?</i></li> </ul> </li> <li>6. Invite a volunteer to read the 3<sup>rd</sup> case study to the entire group (the 3<sup>rd</sup> case study lends itself more to discussion than role play); invite the group to discuss the healthcare worker’s potential responses to the client, using the question in number 5, above.</li> <li>7. (Optional) Encourage participation from the adolescent co-trainer, who can either act as the client in one of the role plays or comment on how he or she might have reacted in a similar situation. Ask the adolescent co-trainer the following questions: <ul style="list-style-type: none"> <li>• <i>How did you feel during this exercise? Were you satisfied with how the healthcare worker tried to build rapport?</i></li> <li>• <i>What did the healthcare worker do well?</i></li> <li>• <i>What could the healthcare worker have done differently? What else could he or she have done to establish trust with you?</i></li> </ul> </li> </ol>
<b>Debriefing</b>	<ul style="list-style-type: none"> <li>• Summarise the exercise by noting that, as healthcare workers, our effectiveness with adolescents depends entirely on how well we engage them and make them</li> </ul>

	<p>feel comfortable.</p> <ul style="list-style-type: none"> <li>Establishing trust and rapport with adolescents can be challenging, but is crucial to facilitating discussion about important health issues, supporting their retention and adherence, and ensuring that their needs are adequately addressed.</li> </ul>
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### **Exercise 1: Establishing Rapport and Building Trust: Role play and large group discussion**

#### **Case Study 1**

Mary is 18 years old and has recently found out that she is HIV infected. She has not disclosed her HIV status to anyone and is very concerned that you might tell her partner. How do you proceed with Mary?

#### **Key points for trainers: Mary**

- The “healthcare worker” should focus on ensuring that Mary knows that her or his job is to meet *Mary’s* needs (not her partner’s needs). The healthcare worker should tell Mary that any discussion between them is confidential, which means that he or she is obligated to keep the discussion private unless Mary gives permission otherwise.
- The “healthcare worker” should listen carefully to Mary’s reasons for not wanting her HIV status disclosed to her partner. The “healthcare worker” should listen carefully for a fear of violence or rejection.
- The “healthcare worker” will need to put effort into establishing a trust with Mary and reassure her of the clinic’s guidelines around confidentiality.
- The “healthcare worker” should communicate that he or she understands and respects Mary’s decision to not disclose.
- The “healthcare worker” should also level with Mary on how he or she feels about disclosure (for the moment, they can agree to disagree). Even though he or she may feel it is important that the partner be informed of his risk of HIV, the “healthcare worker” cannot disclose without Mary’s permission: it would be counterproductive in terms of meeting Mary’s needs right now (remember the “healthcare worker’s” primary aim is to meet Mary’s healthcare needs). If the “healthcare worker” is honest in stating his or her opinion it is more likely that Mary will believe he or she is honest in his or her promise to keep her diagnosis confidential.
- The “healthcare worker” should let Mary know that if she chooses not to disclose at this point in time, that it’s OK, the “healthcare worker” will accept a compromise. For example, it may be sufficient for the time being if Mary promises to ensure her partner uses condoms every time.
- Mary should also think about using, if she doesn’t already, a back up contraception such as the pill.
- The “healthcare worker” should reassure Mary how he or she can help her: advise her on how to disclose, role play various scenarios,

disclose on her behalf, etc.

- Assuming it is safe for her to do so, the “healthcare worker” should also note that Mary’s long term goal should be to disclose to her partner and convince her partner to seek HIV testing. The “healthcare worker” should also reassure Mary that he or she will not pressure Mary to do this, particularly if disclosure puts her at risk of domestic violence.

### **Case Study 2**

Ethel is 15-years-old and living with HIV. She has been living with HIV since she was an infant. Her mother passed away a few years ago and now she lives with her father. She is responsible for caring for her 3 younger siblings. She comes to the clinic today, claiming she has some stomach pains. You suspect the real reason that she has come is because she wants to talk about something. How do you proceed with Ethel?

#### **Key points for trainers: Ethel**

- The “healthcare worker” should ensure this visit goes as any other standard visit might go, ensuring that that Ethel proceeds through the typical clinical visit.
- When it comes time to see the counsellor, the “healthcare worker” should ensure that he (let’s assume the “healthcare worker” is a man this time) carves out sufficient time with Ethel. The “healthcare worker” should start the session in the usual manner.
- If Ethel doesn’t discuss what seems to be bothering her, the “healthcare worker” should ask something like the following: “Ethel you seem \_\_\_\_\_ (fill in with the emotion observed, for example worried, angry, tired, overwhelmed), would you like to talk about it?” If Ethel goes ahead and discusses the “healthcare worker” would continue the session using the 5 “As”.
- If Ethel denies that anything is wrong, then the “healthcare worker” should first remind Ethel that their discussion is confidential, and define what this means.
- To encourage and give Ethel space to talk, the healthcare worker should feel comfortable using silence — whereby the “healthcare worker” just looks expectantly at Ethel and waits for 60–90 seconds to see if she decides to open up. The other technique is for the “healthcare worker” to just ask Ethel, “If you did have something that you really wanted to talk about, what could I do to reassure you that the conversation will be confidential?” “Is there anyone else in your life that you can talk to, maybe a friend?” “Is there anyone else here at the clinic that you’d prefer to talk with today (keep in mind that the “healthcare worker” is a man, if Ethel is, for example worried that she’s pregnant, maybe she’d prefer to talk to a female healthcare worker)?” “Shall I refer you to a counsellor?”

### Case Study 3

Katib is a 10-year-old boy with perinatally-acquired HIV infection. He is an orphan and has been brought to the clinic for an appointment by his grandmother. He is very shy and seems uncomfortable being in the clinic and he doesn't talk with the other adolescent children. How do you proceed with Katib?

#### Key points for trainers: Katib

- Assuming that Katib's health is stable, his adherence good, and he is not at risk of infecting anyone else (as in Case Study 1), the "healthcare worker" should take her (let's assume the "healthcare worker" is a woman) time to get to know Katib.
- The "healthcare worker" should meet with Katib and his grandmother at each visit, given that there's no urgency, she should allow Katib to be quiet in the first session or two. Ask him about something that he cares about (football, cars, favourite hobby, school, siblings, etc) to engage him in conversation. Even if Katib responds with a two word answer, it's fine. Believe it or not, even a two word response indicates progress. In the early stages, the "healthcare worker" should just be aiming to be liked by Katib, not necessarily to get him to talk.
- During the first 1 or 2 meetings, try to discern if Katib is quiet all the time or if he is just quiet around his grandmother. If the later, there may be issues with the relationship that need further discussion.
- During these early meetings, the "healthcare worker" should mention that she is available to meet Katib one-to-one if he would like. The "healthcare worker" should let Katib know when she is available to meet with him and let Katib know that if and when they meet, that meeting will be confidential. .
- Eventually (maybe the 2<sup>nd</sup> or 3<sup>rd</sup> visit, if it feels comfortable) the "healthcare worker" should ask permission from the grandmother to meet with Katib on a one-to-one basis after she meets with him and his grandmother. (If permission is denied, then at the next visit the "healthcare worker" should just tell the grandmother that she needs to meet with Katib alone for 5 minutes.) It is during these one-to-one meetings that the "healthcare worker" will be able to figure out if Katib is always shy or only shy around his grandmother. In these one-to-one meetings it might be sufficient to simply ask Katib: *"Is it OK if we meet without your grandmother sometimes?" "What other questions do you have about HIV?" "What other questions do you have about today's clinic visit?"*
- During the one-to-one meetings, the "healthcare worker" may want to try some age appropriate communication techniques/practical suggestions to build relationship (i.e., storytelling or playing a game).
- During these one-to-one meetings the "healthcare worker" should

define confidentiality, reassuring Katib that what they discuss will not be reported to his caregiver, unless he gives permission.

- Eventually the “healthcare worker” may want to ask more personal questions, such as, “*What’s your best friend’s name?*” “*What do you and \_\_\_\_\_ like to do?*” “*How would YOU say school is going?*” “*Your grandmother tells me that you are not doing well in maths, would you like to talk about that?*” (See “Appendix 3B: HEADSS Interview Questions” in Module 3 for additional questions.)
- Clients who are shy around caregivers will open up as soon as they are away for the caregivers. Whereas clients who are shy in general will take months, sometimes even years to open up.



### **Trainer Instructions**

**Step 6:** Allow 5 minutes for questions and answers on this session.

## Session 4.2

# Effective Techniques for Counselling Adolescents



**Total Session Time:** 135 minutes (2 hours, 15 minutes)



### Trainer Instructions

Slides 18-19

- Step 1:** Begin by reviewing the session objective listed below.
- Step 2:** Ask participants if there are any questions before moving on.

### Session Objective

**After completing this session, participants will be able to:**

- Demonstrate effective counselling skills.



### Trainer Instructions

Slides 20-24

- Step 3:** Now that we have talked about how to build trust and rapport with clients — the first step in the counselling process — we will now discuss how to communicate effectively with clients.
- Ask participants to briefly reflect on a time when they received good counselling — from a friend, a colleague, or a counsellor. Ask the following questions to facilitate discussion about the components of “good counselling”:
- *What is counselling?*
  - *What does good counselling include? What does it not include?*
- Fill in key points, as needed. Also encourage participants to review “Appendix 4A: Common Counselling Mistakes” for a listing of typical counselling mistakes.
- Step 4:** (optional) Ask the adolescent co-trainer the following questions to encourage his or her input:
- *Do you remember an occasion when you received counselling that you would consider very good? Why was it good?*



### **Make These Points**

- Counselling is a way of working with people to understand how they feel and to help them decide what they think is best to do in their situation.
- The role of healthcare workers is to support and assist the client's decision-making process.
- Healthcare workers are not responsible for solving all of the client's problems.
- Ultimately, it is the responsibility of the client to decide upon and carry out her or his own decision or solution.

## **Overview of Counselling and Communication**

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### **Why do we do counsel someone?**

- To help people talk about, explore, and understand their thoughts and feelings
- To help people work out for themselves what they want to do and how they will do it

### **Counselling includes:**

- Establishing supportive relationships
- Having conversations with a purpose (not just chatting)
- Listening carefully
- Helping people tell their stories without fear of stigma or judgement
- Giving correct and appropriate information
- Helping people to make informed decisions
- Exploring options and alternatives
- Helping people to recognise and build on their strengths
- Helping people to develop a positive attitude toward life and to become more confident
- Respecting everyone's needs, values, culture, religion, and lifestyle
- Being willing to trust client's feelings and decisions, which may be the right ones for them in their situation and at that time.

### **Counselling does NOT include:**

- Solving another person's problems
- Telling another person what to do
- Making decisions for another person
- Blaming another person
- Interrogating or questioning another person
- Judging another person
- Preaching to, or lecturing, another person
- Making promises that cannot be kept

- Imposing one's own beliefs on another person
- Providing inaccurate information



### **Trainer Instructions**

Slides 25-28

#### **Step 5:**

Remind participants that their counselling and communication approach will be slightly different for each client. For example, counselling older adolescents is very different than counselling younger adolescents. Some younger adolescents may want to express their thoughts and feelings but have difficulty verbalising them. Ask participants:

- *What else do you think you need to consider when talking to younger adolescents?*
- *What do you think you need to consider when talking to older adolescents?*
- *In your professional or personal experience, what have you done to communicate effectively with younger adolescents and to help them express themselves?*

Record responses on flip chart and fill in using the content below. Refer participants to “Appendix 4B: General Tips on How to Talk With Adolescents” and “Appendix 4C: Basic Counselling Guidance for ALHIV”.



### **Make These Points**

- Healthcare workers need to adjust their counselling and communication style to the adolescent they are counselling, keeping in mind his or her age and developmental stage.
- Some effective ways of communicating with all adolescents include: giving real-life examples through storytelling, reducing stigma around a sensitive topic by normalising issues, using indirect questions, speaking about non-threatening topics before sensitive ones, and encouraging and offering opportunities for peer support.
- When counselling younger adolescents, be patient, use simple language, allow plenty of time to build rapport, and use creative activities to encourage expression, such as reading or storytelling, drawing, or doing something fun.

## Communicating with Adolescents

### General tips on communicating with adolescents<sup>2</sup>:

- **Start the counselling session by talking about non-threatening issues:** Begin by establishing rapport (see Session 4.1) and asking questions about the adolescent's home, family, school and even hobbies, before moving on to more sensitive topics, like adherence to medication, disclosure, and sexual or reproductive health issues.

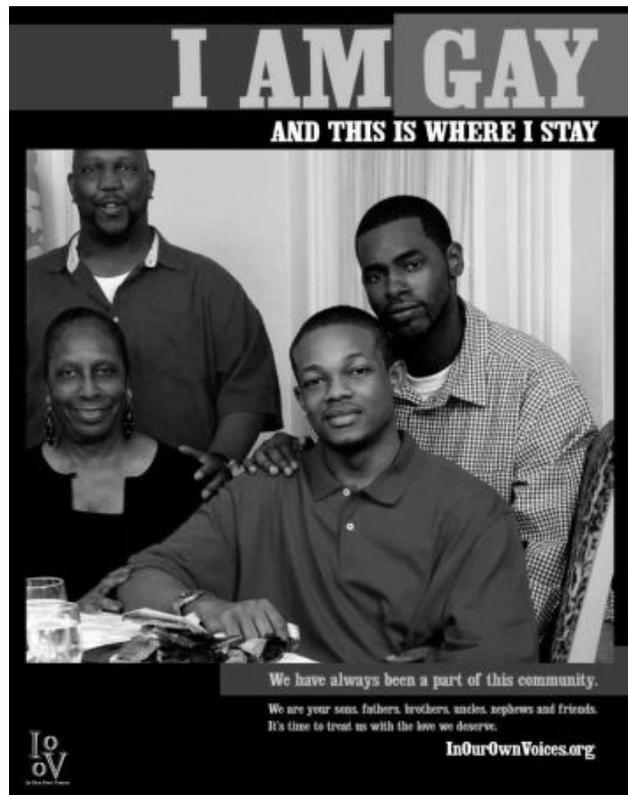
- **Use a third person (indirect questions):** Initially, ask about activities of peers and friends rather than asking direct questions about their own behaviour: *"Do any of your friends smoke pot/dagga?"* *"Have you ever joined them?"*

- **Reduce stigma around an issue by normalising it:** An adolescent who is living with HIV with may feel embarrassed seeking help with various issues, but you can reduce stigma and feeling of shame by saying: *"I have treated a number of young people who are also living with HIV. I'm here to help you."* *"I ask all of my clients if they are having sex so I can make sure they get the information and services you need. Some adolescents are in sexual relationships and others are not. Whether your answer is yes or no, it is OK and I want you to feel comfortable talking with me about these personal things."* Another way to reduce stigma is to use posters in common areas that communicate important messages in an eye-catching, youth-friendly manner, see Figure 4.1: "I am gay" poster,

as an example. The logo at the bottom of the poster reads "We have always been a part of this community. We are your sons, fathers, brothers, uncles, nephews and friends. It's time to treat us with the love we deserve." A poster such as this would communicate to a young homosexual man that the clinic is gay-friendly, making him more likely to open up about his sexuality.

- **Repeat information through questions:** You can repeat information that sounds irrational and unreasonable back to an adolescent in the form of a question. For example, an adolescent might say, *"I do not care that my cousin stopped talking to me when I told him I had HIV. I do not*

Figure 4.1: "I am gay" poster



*need him.*" Instead of saying, "Of course you care," and pushing the client away, you could respond by asking, "So it doesn't bother you that your family is giving you a hard time? How does it make you feel?" When put into a question, many adolescents re-think and reflect about the statement they just made.

- **Encourage peer support:** Encourage adolescents to discuss issues with peers who are also infected with HIV, either one-to-one or in groups. Peer support helps adolescents recognise that they are not alone in dealing with their problems. An ALHIV may not respond to an adult who tells him to take his medication every day; but he might listen to a peer. Using other adolescents who have struggled with the same problems related to care and treatment, like adherence challenges or disclosure, can be extremely effective motivator (see Session 5.3 for more information about peer support).

### **Considerations when communicating with younger adolescents**

- Younger adolescents need time to feel safe and to trust. Try starting the session by doing something together, like playing a game.
- Younger adolescents understand concrete things that they can touch and see. Drawing, demonstration, or visual aids can be used to make information more concrete.
- They may feel scared and fear being judged.
- They may feel anxious or embarrassed when asking for help
- They need some time to observe you! Do not expect they will instantly talk. Allow plenty of time and be patient.
- Explain things in simple terms.
- Just because the adolescent is not asking questions, does not mean he or she is not thinking about what is being said.
- Do not force the adolescent to share. Positively reinforce the adolescent's effort to express him or herself.
- If a youth is rude or aggressive, remember that it may not be directed at you. He (or she) may be feeling angry with adults for treating him badly or letting him down. Be patient and don't take it personally.
- Give young adolescents as much time as necessary.

### **Activities to promote expression with younger adolescents:**

- **Storytelling or reading together:** The healthcare worker could read or tell a story (such as that in Table 4.1: Monde's story) during a group or individual counselling session. Following the story, the healthcare worker asks key questions to encourage thought and discussion.

**Table 4.1: Monde's story**

**Monde's story**

*Monde is a 16 year old girl living in Lusaka, the capital of Zambia. Like many teenagers, she goes to school, hangs out with friends and has a boyfriend. However, there is something that people don't know about her: she is HIV positive. Although Monde was born with HIV, because of taking ART she has reached adolescence and is hoping to attend university in a couple years. She lives at home with her mother, who is also HIV positive, and two younger siblings who are not. Her dad died when she was little.*

*None of her friends knows she is HIV positive, and she is scared that if they knew, they wouldn't want to hang around with her anymore. Monde really loves her boyfriend, Bwalya, and spends a lot of time with him. They sometimes kiss, and he often wants to go further but she tells him that she doesn't believe in sex before marriage. Monde is starting to feel this pressure, but she doesn't know what to do. There is a part of her that really does want to sleep with her boyfriend. She really does love him. But she is worried that she will give him HIV. She doesn't know how to get condoms, and she heard that boys don't like using condoms. She doesn't know how to tell him that she has HIV. What if she tells him and he leaves her and tells all her friends? Her whole world would fall apart!*

What do you think Monde should do?

Adapted from: Ross, J. 2010. Needs, Challenges and Opportunities: Adolescents and Young People Living with HIV in Zambia. International HIV/AIDS Alliance and Evidence for Action.

- **Journaling:** Encourage clients to keep a journal or a diary. The journal is a place where the adolescent can write about what is happening in their lives and how they feel about it (for example, *How I would describe myself? Last week I felt.....because....*).
- **Drawing:** Encourage clients to draw a picture of their families or their homes. The healthcare worker should then ask questions about the drawing to communicate interest and encourage expression:
  - “Tell me about your drawing”
  - “What happened here?”
  - “How did you feel then?”
- **Letter writing:** Encourage adolescent clients to write letters to a friends or family members about what is happening or how they are feeling.
- **Doing something fun:** Initiate something fun while you are talking. This could include playing a game, playing cards, taking a walk, pursuing a hobby (making a toy, knitting, hand sewing, etc), or playing a sport. Young people often feel more comfortable talking when discussion is secondary to something else they are doing.



### **Trainer Instructions**

Slides 29-37

**Step 6:** Continue by explaining that clear and effective communication is the key to good counselling. Explain that the 7 basic listening and learning skills routinely used by healthcare workers are the building blocks for counselling and effective communication with their clients.

Discuss each of the 7 skills and explain why each is important for quality counselling. Trainers should then briefly role play what to do and what not to do for each skill, using the script provided in Table 4.3, Table 4.4, Table 4.5, and Table 4.6.

After you present each skill, ask a participant to give an additional example. Participants giving examples may recall a time when they used or did not use this skill and what happened as a result. Alternatively, participants can try to illustrate the skill by describing a scenario or by role playing. Encourage participants to review “Appendix 4D: Listening and Learning Skills Checklist,” as they observe the basic listening and learning skills demonstrations.

**Step 7:** (optional) Invite the adolescent co-trainer to role play the client as another trainer demonstrates the basic listening and learning skills.



### **Make These Points**

- As healthcare workers, we need to use good communication skills to engage and help our clients.
- The 7 listening and learning skills are the building blocks of good communication for healthcare workers.
- Active listening includes both verbal and non-verbal forms of communication.
- The use of helpful non-verbal communication, open-ended questions, actively listening, and reflecting back can be used as tools to encourage clients to openly discuss their issues and concerns.
- The use of empathy — which shows that the healthcare worker understands how the client feels — and the use of words that build confidence and give support (rather than judge), illustrate understanding and caring.
- Finally, “Skill 7: Help the client set goals and summarise each counselling session” is a chance to work with the client to develop next

steps and to reiterate key points from the session.

## Listening and Learning Skills<sup>3,4,5</sup>

Good counsellors use verbal and non-verbal listening and learning skills to help clients through their process of exploration, understanding and action. Therefore, when communicating with and counselling clients, healthcare workers should:

- Skill 1: Use helpful non-verbal communication
- Skill 2: Actively listen and show interest in the client
- Skill 3: Ask open-ended questions
- Skill 4: Reflect back what the client is saying
- Skill 5: Empathize — show that you understand how the client feels
- Skill 6: Avoid words that sound judging
- Skill 7: Help the client set goals and summarise each counselling session

For additional information, refer participants to “Appendix 4B: General Tips on How to Talk With Adolescents”, “Appendix 4C: Basic Counselling Guidance for ALHIV”, and “Appendix 4D: Listening and Learning Skills Checklist”.

### Skill 1: Use helpful non-verbal communication

Non-verbal communication refers to all aspects of a message that are not conveyed by the literal meaning of words. It includes the impact of gestures, gaze, posture and expressions capable of substituting for words and conveying information. Non-verbal communication reflects attitude. Helpful non-verbal communication encourages the client to feel that the healthcare worker is listening and cares about what is being said.

The acronym “ROLES”, as shown in Table 4.2: ROLES, can be used to help remind healthcare workers of behaviours that convey caring.

**Table 4.2: ROLES**

Non-verbal behaviour that conveys caring	
<b>R</b>	A <b>relaxed</b> and natural attitude with clients is important. Do not move around quickly or chat nervously.
<b>O</b>	Adapt an <b>open posture</b> . Crossing one’s legs or arms can signal that you are critical of what the client is saying or are not listening. Using an open posture shows that you are open to the client and to what the client is saying.
<b>L</b>	<b>Leaning forward</b> toward the client is a natural sign of involvement.
<b>E</b>	Culturally appropriate <b>eye contact</b> should be maintained to communicate interest; never stare or glare at the client.
<b>S</b>	<b>Sitting squarely</b> facing another person shows involvement. If for any reason this may be threatening, then sitting to the side is an

option.
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These physical behaviours convey respect and genuine caring. However, these are guidelines, and should be adapted based on cultural and social expectations.

**Table 4.3: Examples of non-verbal communication**

<b>What not to do</b>	<b>What to do</b>
Female adolescent client walks in <b>Healthcare worker (HCW):</b> <i>Hello. My name is _____ (name). (HCW keeps working at computer and sits behind desk.)</i>	Female adolescent client walks in <b>Healthcare worker (HCW):</b> <i>Hello. My name is _____ (name). (HCW keeps working at computer.)</i>
<b>Adolescent:</b> <i>I have a question I wanted to ask you about.</i>	<b>Adolescent:</b> <i>I have a question I wanted to ask you about.</i>
<b>HCW:</b> <i>Please sit down (speaking in a hurried fashion). What is your question (still looking at the computer and keyboard)?</i>	<b>HCW:</b> (looks at adolescent, stops working at her computer and moves chair so that it is not behind the desk) <i>Please sit down. What was your question (leaning forward, not crossing legs).</i>
<b>Adolescent:</b> <i>Well, I just started seeing someone...a boy. And, I was wondering... (her voice trails off)</i>	<b>Adolescent:</b> <i>Well, I just started seeing someone...a boy. I was wondering if you thought it might be OK if I don't tell him I have HIV just yet.</i>
<b>HCW:</b> no response (still typing at computer)	<b>HCW:</b> looks warmly, yet with concern, at adolescent. (Optional: demonstrate appropriate touch.)
<b>Adolescent:</b> clears throat to get HCW's attention	
<b>HCW:</b> <i>Oh sorry (she finally stops typing and looks at watch). Yes, go ahead, you had a question about some girl friend of yours? (HCW's hands are folded, legs crossed and facing away from adolescent, looking across the room, with expression suggesting disinterest.)</i>	<b>HCW:</b> <i>You look concerned, as if you think this may not be the right decision. Tell me a bit more about why you'd prefer to wait to disclose to him (speaking in a warm voice, looking at adolescent, leaning forward, not crossing legs).</i>
<b>Adolescent:</b> <i>Well no, actually it was a boy, not really a boyfriend ... yet, anyhow. Actually it's OK. Don't worry, sorry to have bothered you.</i>	<b>Adolescent:</b> Proceeds to explain her perspective.
Note that in the first skit (Hinders non-verbal communication), the adolescent walked out, giving up on her attempt to get advice on disclosure. In the second skit (Helpful non-verbal communication), the adolescent feels free to ask her questions.	

## Skill 2: Actively listen and show interest in the client

Another way to show that you are interested and want to encourage a client to talk is to use gestures such as nodding and smiling, responses such as “Mmm”, or “Aha” and skills such as clarifying and summarising. These skills, also referred to as attending skills, demonstrate that the healthcare worker is actively listening to the client. These behaviours invite the client to relax and talk about herself or himself.

**Clarifying:** Clarifying prevents misunderstanding and helps sort out what has been said. For example, if an adolescent says: “All my friends will drop me if they find out I have HIV!” the healthcare worker may ask “Tell me more about why disclosing to your friends is a concern for you”.

**Summarising:** Summarising pulls together themes of the counselling discussion so that the client can see the whole picture. It also helps to ensure that the client and the healthcare worker understand each other.

- Healthcare workers should review the important points of the discussion and highlight any decisions made.
- Healthcare workers can summarise key points at any time during the counselling session, not only at the end.

Summarising can offer support and encouragement to clients to help them carry out the decisions they have made related to their own health and well-being.

**Table 4.4: Example of actively listening and showing interest**

What to do	
<b>HCW:</b>	<i>Hey, you seem down today. What’s going on?</i>
<b>Male adolescent client:</b>	<i>It’s school, I don’t want to go any more.</i>
<b>HCW:</b>	<i>umhummm*</i> (nods understandingly)
<b>Adolescent:</b>	<i>Well, it’s not really school, it’s the kids at school. I don’t have any friends.</i>
<b>HCW:</b>	<i>So, you dread going to school because you feel like you don’t fit in?***</i>
<b>Adolescent:</b>	<i>Yea, the other children make fun of me. They call me “shortie” and “crybaby”.</i>
<b>HCW:</b>	<i>umhum*</i>
<b>Adolescent:</b>	<i>Yesterday one of the bigger boys even pushed me to the ground.</i>
<b>HCW:</b>	<i>That’s terrible. It seems to me that the other boys are bullying you. What one thing would you like to change to make this situation better?***</i>
*	A gesture that shows interest
**	Clarifying
***	Summarising

### Skill 3: Ask open-ended questions

Asking questions helps identify, clarify and break down problems into smaller, more manageable parts. Open-ended questions begin with “how”, “what”, “when”, “where” or “why”. Open-ended questions encourage responses that lead to further discussion, whereas closed-ended questions tell a client the answer that you expect; responses are usually one-word answers such as, “Yes” or “No”. Closed-ended questions usually start with words like “are you?” “did he?” “has she?” “do you?”

Healthcare workers should try to avoid questions that have a yes or no answer. For example, instead of asking, “Are you concerned about talking to your family about your diagnosis?” you may ask, “What concerns do you have about talking to your family about your HIV test results?” Or, instead of “Are you taking your ARVs?” you may ask, “How many times have you taken your ARVs in the last 3 days?”

**Table 4.5: Examples of open- and closed-ended questions**

What not to do	What to do
Female adolescent client walks in <b>HCW:</b> <i>Hi, how are you? I'm _____ (name), the counsellor. As you will be starting ART soon, I thought that today we could talk about adherence.</i>	Female adolescent client walks in <b>HCW:</b> <i>Hi, how are you? I'm _____ (name), the counsellor. As you will be starting ART soon, I thought that today we could talk about adherence.</i>
<b>Adolescent:</b> <i>OK</i>	<b>Adolescent:</b> <i>OK</i>
<b>HCW:</b> <i>Do you know what we mean by “adherence”?</i>	<b>HCW:</b> <i>What do we mean when we refer to “adherence”?</i>
<b>Adolescent:</b> <i>Yea, I think so.</i>	<b>Adolescent:</b> <i>Well, I'm not sure, is it about sticking to your medicine?</i>
<b>HCW:</b> <i>Great! Do you think you will be able to adhere to your ART regimen?</i>	<b>HCW:</b> <i>Kind-of. It's about sticking to your ART regimen by taking your ARVs every evening and every morning exactly as recommended. What do you think you can do to remember to take are ARVs every morning and evening?</i>
<b>Adolescent:</b> <i>Yes, probably.</i>	<b>Adolescent:</b> <i>Well, I'll keep my pills on the table where we eat, that will remind me to take them with breakfast and again at dinner time. I'll remember because they are right there.</i>
<b>HCW:</b> <i>And will you have an adherence buddy to help you remember?</i>	<b>HCW:</b> <i>That sounds like a good plan, we'll see how it works. Who will you buddy to help you remember to take your medications?</i>
<b>Adolescent:</b> <i>Yes, I guess so.</i>	<b>Adolescent:</b> <i>My mother will help me remember.</i>
In the first skit (Hinders), the close-ended questions are conversation	

stoppers; this client left the session without a concrete adherence plan and possibly a misunderstanding of what the term “adherence” means. Whereas in the second skit (Helps Open-ended questions), the same client was required to come up with a plan before responding to the HCW’s questions. She left the session with a concrete plan to help her remember to take her medications every day and a named adherence buddy to provide back up. At the follow-up visit the HCW can enquire about how the plan worked.

#### **Skill 4: Reflect back what the client is saying**

"Reflecting back", also referred to as paraphrasing, means repeating back what a client has said to encourage him or her to say more. Try to say it in a slightly different way. For example, if a client says, *“I am not able to tell my boyfriend about my HIV status,”* the healthcare worker may reflect by saying, *“Talking to your partner sounds like something that you are not comfortable doing right now”*. After the client confirms that this is an accurate reflection of what she or he said, the healthcare worker can then say, *“Let’s talk about that some more”*.

For example, the counsellor can use the following formulas for reflecting:

- *“You feel \_\_\_\_\_ because \_\_\_\_\_.”*
- *“You seem to feel that \_\_\_\_\_ because \_\_\_\_\_.”*
- *“You think that \_\_\_\_\_ because \_\_\_\_\_.”*
- *“So I sense that you feel \_\_\_\_\_ because \_\_\_\_\_.”*
- *“I’m hearing that when \_\_\_\_\_ happened, you did not know what to do.”*

Reflecting back shows that the healthcare worker is actively listening, encourages dialogue, and gives the healthcare worker an opportunity to understand the client’s feelings in greater detail. See “Table 4.4: Example of actively listening and showing interest” for an example of reflecting back.

#### **Skill 5: Empathize — show that you understand how the client feels**

Empathy develops when one person is able to comprehend (or understand) what another person is feeling. Empathy, however, is not the same as sympathy; sympathy implies that you feel sorry for (pity) the other person.

Empathy is needed to understand how the client feels and helps to encourage the client to discuss issues further. For example, if a client says, *“I just cannot tell my partner that I have HIV!”* the healthcare worker could respond by saying *“It sounds like you might be afraid of your partner’s reaction.”* Another example is if a visibly upset client says: *“My partner argues with me all the time about using condoms! I’m so sick of fighting with him”* the healthcare worker could respond by saying: *“That must be really*

upsetting. It sounds like you feel very frustrated with him. ” If the healthcare worker responds with a factual question, for example, “How often do you have these kinds of fights about condoms?” the client may feel that the healthcare worker does not understand because the healthcare worker’s response was not in reference to the underlying feelings.

Empathy is used to respond to a statement that is emotional. When empathizing, the healthcare worker identifies and articulates the emotion behind a client’s statement. Whereas, “Skill 4: Reflect Back what the Client Says” is used to summarise conversation that is primarily factual.

**Table 4.6: Examples of empathy**

What not to do	What to do
<b>HCW:</b> <i>What do you think about asking your partner to use condoms?</i>	<b>HCW:</b> <i>What do you think about asking your partner to use condoms?</i>
<b>Female adolescent:</b> <i>To be honest, I’m scared. I actually think he might hit me.*</i>	<b>Female adolescent:</b> <i>To be honest, I’m scared. I actually think he might hit me.*</i>
<b>HCW:</b> <i>Yea I know what you mean, that happened to my sister. She actually did ask her boyfriend to use condoms and you know what? He hit her then he made her leave the house. He didn’t let her come back for two full days.***</i>	<b>HCW:</b> <i>It sounds like you’re often scared of your boyfriend.**</i>
<b>Adolescent:</b> (Silent, waiting for HCW to continue her story.) <i>So did your sister go back?</i>	<b>Adolescent:</b> <i>You’re right, I am. It’s not just about asking him to use condoms, I’m also fearful that he’ll be upset if I even talk to another boy, if I forget to call him after school, if I’m home even one minute late, or for a lot of other reasons.</i>
* Notice that the client is discussing how she feels; empathy is a skill used to respond to the underlying feelings expressed by the client.	
** Notes the empathetic response. The empathetic response encourages the client to further discuss the issue.	
*** This statement is more sympathising rather than empathizing; it changes the subject of the discussion from the client to the HCW’s sister.	

### Skill 6: Avoid judging words

Judging words are words like: *right, wrong, well, badly, good, enough* and *properly*. If a healthcare worker uses judging words when asking questions, adolescent clients may feel that they are wrong or that they should respond in a certain way to avoid disappointing the healthcare worker. Healthcare workers should also avoid phrasing a question in a way that is judging, that is, in a manner that leads the client to respond in a certain way for fear of disappointing the questioner. See examples below.

Examples of what **NOT** to do:

### Examples of using judging words

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<b>Healthcare worker:</b>	<i>Did you listen to me and use a condom?</i>
<b>Client:</b>	<i>Um...yes.</i>
<b>Healthcare worker:</b>	<i>Did you take your medicine correctly (or properly)?</i>
<b>Client</b>	<i>I think so.</i>
<b>Healthcare worker:</b>	<i>Didn't you understand what I told you about taking your medicine?</i>
<b>Client:</b>	<i>I don't know, I think so.</i>
<b>Healthcare worker:</b>	<i>Did you follow my recommendation to talk to your mother about your HIV status? (Or "Did you do the right thing and talk to your mother about your HIV status?")</i>
<b>Client:</b>	<i>Well, yes, I tried to speak with her....</i>

Notice in these examples that the client has not fully responded to the healthcare worker's questions. Instead, the healthcare worker is making the client uncomfortable. It is quite likely that the client may provide the healthcare worker with a misleading response for fear of being judged.

Note that the client may use judging words and this is acceptable (for example, "I was not brave enough to talk to my mother. I only told my sister.") When a client does use judging words, do not correct him or her, but do not agree with her either. Instead, the response should aim to build her confidence through praise, for example, "I was impressed that you were able to talk with your sister. That is a big step."

More helpful examples, using open-ended questions and avoiding judging words, could be as follows:

### Examples of using non-judging words

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<b>Healthcare worker:</b>	<i>What form of family planning, if any, did you use the last time you had sex?</i>
<b>Healthcare worker:</b>	<i>At about what time yesterday did you take your ARVs? How about the day before yesterday?</i>
<b>Healthcare worker:</b>	<i>What has been your experience with taking ART?</i>

**Healthcare worker:** *Can we go back to our discussion on disclosure?  
Who have you told about your HIV test result since  
your last visit?*

However, sometimes a healthcare worker needs to use “good” judging words to build a client’s confidence, and to recognise and praise the client when she or he is doing the right thing.

#### **Example of using judging words to build confidence**

**Healthcare worker:** *You are doing a great job remembering to come to your appointments.*

**Healthcare worker:** *You are doing the right thing for yourself and your baby by taking your ARVs.*

### **Skill 7: Help the client set goals and summarise each counselling session**

Toward the end of a session, the healthcare worker works with the adolescent client to come up with “next steps” and summarise the session:

- **Develop “next steps”.** The healthcare worker could initiate this part of the discussion by stating, “Okay, now let’s think about the things you will do this week based on what we talked about.” To help the client develop a more specific plan, the healthcare worker could ask:
  - *What do you think might be the best thing to do?*
  - *What will you do now?*
  - *How will you do this?*
  - *Who might help you?*
  - *When will you do this?*

#### **Next steps and goals should:**

- Be developed by the healthcare worker and client together
- Empower the client to achieve what he or she wants by agreeing to realistic short- and long-term goals and actions
- Provide direction and must be results-oriented
- Be clear enough to help the client measure his or her own progress (people feel good when they achieve something they have set out to do)

- **Summarise the client’s plan and review next steps.** The healthcare worker could say, “I think we’ve talked about a lot of important things today. (List main points.) We agreed that the best next steps are to \_\_\_\_\_.  
*Does that sound right? Let’s plan a time to talk again soon.”*
- **Give the client a chance to ask questions.**
- **Make referrals,** if needed.
- **Make an appointment for return visit:** Discuss when the client will return and make sure she or he has an appointment.



### Trainer Instructions

Slides 38-43

**Step 8:** Lead participants through Exercise 2, which will provide them with an opportunity to practise the 7 listening and learning skills.

### Exercise 2: Practise Listening and Learning Skills: Case studies in small groups and large group discussion

<b>Purpose</b>	<ul style="list-style-type: none"> <li>To provide participants with an opportunity to gain experience using listening and learning skills with adolescent clients</li> </ul>
<b>Duration</b>	60 minutes
<b>Advance Preparation</b>	<ul style="list-style-type: none"> <li>Read through and adapt the case studies as needed.</li> <li>Identify an experienced participant or a co-trainer to demonstrate use of the listening and learning skills using the case study below.</li> <li>Encourage participants to review “Appendix 4D: Listening and Learning Skills Checklist”.</li> </ul>
<b>Introduction</b>	<p>Explain that a healthcare worker’s manner of communicating with the adolescent will play an essential part in determining whether the adolescent will listen or act on the information. In introducing this exercise, remind participants that a good communicator should:</p> <ul style="list-style-type: none"> <li>Use helpful non-verbal communication.</li> <li>Actively listen and show interest in the client.</li> <li>Ask open-ended questions.</li> <li>Reflect back what the client is saying.</li> <li>Empathize — show that you understand how the client feels.</li> <li>Avoid words that sound judging.</li> <li>Help the client set goals and summarise each counselling session.</li> </ul>
<b>Activities</b>	<p><b>Part 1: Trainer Demonstration</b></p> <p>Invite a co-trainer or a volunteer (if possible, someone with counselling training and experience) from the group to role play the “client” as the trainer demonstrates the basic listening and learning skills.</p> <ol style="list-style-type: none"> <li>Place two chairs in square faced position. Ensure that all of the participants can easily observe the role play.</li> <li>Ask participant to use “Appendix 4D: Listening and Learning Skills Checklist” as they observe the basic listening and learning skills demonstration.</li> <li>The trainer (or participant with counselling skills) and the co-trainer (or volunteer) should then take about 5 minutes to role play the following scenario.</li> </ol>

Geraldine, who has had HIV since she was a baby, has been coming to your clinic ever since you can remember. Geraldine, who is now 16, has had the same boyfriend since she was 14, and the relationship is starting to get more serious. The “healthcare worker” has suggested that Geraldine consider telling her boyfriend that she has HIV. Geraldine is scared, she just doesn’t know how to break the news after all these years.

4. They should try to demonstrate each of the listening and learning skills just discussed. (Note to trainers: during the demonstration counselling session, use listening and learning skills to find out what Geraldine thinks about being pregnant, how she feels this affects her future, how she is going to tell her partner and family. Ensure you are NOT judgemental!)
5. Take 5 minutes to debrief with participants using “Appendix 4D: Listening and Learning Skills Checklist”.
6. Ask participants to share their observations and suggestions.
7. (Optional) Encourage participation from the adolescent co-trainer, who can act as the adolescent client in the role plays. Ask the following questions to encourage discussion:
  - *How did you feel during this exercise? Were you satisfied with how the healthcare worker tried to build rapport?*
  - *What did he or she do well?*
  - *What could he or she do differently?*
  - *What else could he or she have done to effectively communicate with you?*

### **Part 2: Small Group Work**

8. Break participants into groups of 3.
9. Each group should review the case studies.
10. Ask participants to:
  - Identify a “healthcare worker/counsellor”, “client” and an “observer” for the first case study.
  - Using the first case study, suggest that the “healthcare workers” initiate the discussion as they would in the clinic setting. Give the “healthcare worker” and “client” about 5 minutes for their session.
  - The “healthcare worker/counsellor” will practise as many of the listening and learning skills

	<p>possible in the 5 minutes provided.</p> <ol style="list-style-type: none"> <li>11. After five minutes, stop the exercise and ask the “observer” to provide feedback on each of the skills and techniques observed using the Listening and Learning Skills Checklist.</li> <li>12. Repeat this exercise using the remaining 2 case studies so that everyone will have an opportunity to practise each role.</li> <li>13. Trainers should circulate around the room during the role plays to ensure that participants are using their listening and learning skills and providing accurate and appropriate support and advice.</li> </ol> <p><b>Part 3: Large Group Discussion</b></p> <ol style="list-style-type: none"> <li>14. Bring participants back to the large group and ask each group to report key findings on things that the “healthcare workers/counsellors” did well and the things they can do to improve their counselling. Also ask: <ul style="list-style-type: none"> <li>• <i>What did you do to build trust and rapport with your client?</i></li> <li>• <i>Which listening and learning skills worked well?</i></li> <li>• <i>Which listening and learning skills did you find difficult?</i></li> </ul> </li> <li>15. Write these on a flip chart and lead an interactive discussion pointing out strengths and possible ways to improve listening and learning skills.</li> </ol>
<b>Debriefing</b>	<ul style="list-style-type: none"> <li>• Summarise the key points from the group feedback.</li> <li>• Remind participants that improving listening and learning skills takes practise, as well as continuous self-exploration.</li> </ul>

**Exercise 2: Practise Listening and Learning Skills: Case studies in small groups and large group discussion**

**Case Study 1:**

Mwape is an 18-year-old client you see regularly at the ART clinic. He tells you that he has a male partner that he sees on the weekends. He is very worried that his family and friends at school will find out that he is HIV infected and is scared about confiding in you. How do you counsel Mwape?

**Key points for trainers: Mwape**

- Ensure you use listening and learning skills to encourage Mwape to discuss not only his issues around disclosure, but also the fact that his primary partner is a male. In a heterosexual world, many people who have same-sex partners feel the spectre of discrimination should this become known.
- Mwape will need reassurance around confidentiality.

- Given that Mwape is “worried” and “scared” the counsellor will need to exhibit empathy skills (“Empathize — show that you understand how the client feels”) as well as the other listening and learning skills.

### **Case Study 2:**

Prudence is a 12-year-old girl who acquired HIV perinatally. Her mother died when she was 5 years old and she has been living with her grandmother ever since. Her grandmother does not like to talk about Prudence’s HIV status, and none of her friends know she has HIV. When you speak to Prudence, she doesn’t say anything, and keeps looking at the floor with her arms crossed. How do you counsel her?

#### **Key points for trainers: Prudence**

- Basically you want to get Prudence to like you. Assuming she likes and trusts the healthcare worker, she will eventually open up and discuss why she is so angry. Start with general (open-ended, of course) questions to encourage her to talk about herself (for example, “What do you think about the local football team, 5 wins in a row!” “What’s your favourite subject in school?”).
- The key is to establish trust — i.e, a key listening and learning skill for today’s session with Prudence — is “Actively listen and show interest in the client”. Once she sees that you are interested in her and can be trusted, then you can use empathy (“Empathize — show that you understand how the client feels”) to ask, for example, “Prudence, you seem angry today, would you mind telling me why?”

### **Case Study 3:**

Gabriel is a 16-year-old who tested positive for HIV 4 weeks ago. When you see him at the clinic today, he appears upset. He says that he hasn’t told anyone about his HIV status and that he feels really angry most of the time. His girlfriend is threatening to break up with him because of his moodiness, and he is not doing well in school. When you question him, he gives you short responses in an angry voice. How do you counsel Gabriel?

#### **Key points for trainers: Gabriel**

- You want to let Gabriel know that anger is a normal part of coming to terms with his HIV status. If you (as the healthcare worker) have met the Gabriel previously (maybe you were the healthcare worker who gave him the test result 4 weeks ago), then you might be able to start this session using your empathy skills (“Empathize — show that you understand how the client feels”). First, acknowledge his anger. Reassure him that this is normal, but then ask, for example, “Can you put your finger on what it is that makes you feel angry right now?”
- If you are meeting Gabriel for the first time, you may want to just start

with getting to know him by asking open-ended questions before using your empathy skills.

- Gabriel may not be ready to talk. If he isn't, ensure that you've communicated to him that you care (through "Use of helpful non-verbal communication", "Actively listening and showing interest" and "Reflecting back what the client is saying").
- When you summarise the counselling session with him, make a follow-up appointment and ensure he knows how to find you should be want to come in before the date of the follow up.



### **Trainer Instructions**

**Step 9:** Allow 5 minutes for questions and answers on this session.

## Session 4.3

# Challenges and Solutions to Counselling Adolescent Clients



**Total Session Time:** 70 minutes (1 hour, 10 minutes)



### Trainer Instructions

Slides 44-45

- Step 1:** Begin by reviewing the session objective, listed below.
- Step 2:** Ask the participants if they have any questions before moving on.

### Session Objective

**After completing this session, participants will be able to:**

- Identify and address common challenges in counselling adolescent clients.



### Trainer Instructions

Slides 46-58

- Step 3:** Continue by explaining that, as we discussed in the last session, the role of the healthcare worker is entirely dependent on his or her ability to effectively establish trust/rapport and communicate with the adolescent. Ask the following questions to facilitate discussion:
- *In your experience, what are some common communication challenges that can occur with adolescents and healthcare workers? What about challenges that might be unique to ALHIV? Why do you think these happen?*
  - *What are some other challenges that exist in your clinic, related to the communication and counselling process (for example, lack of space, time constraints)?*
  - *What have you done or can you do given current resources to overcome these challenges?*
- Brainstorm about common communication challenges and strategies healthcare workers have used to overcome them, using the content below. Record responses on a flip chart.
- Step 4:** (optional) Ask the adolescent co-trainer to share an example of a time when he or she had difficulty communicating or sharing their feelings with an adult or healthcare worker. Ask the

following questions to encourage his or her input and participation:

- *Why did you find it difficult to communicate with the person?*
- *How did the person respond to you?*
- *What did they do that was helpful? Unhelpful?*



### **Make These Points**

- There can be many challenges to providing quality counselling in adolescent HIV care and treatment clinics, including an adolescent's behaviours, moods, or even lack of time and private counselling space in the clinic.
- Some adolescents may come to the clinic on their own or some may come with friends or relatives. Others may be brought to see you by a caregiver or another adult. Depending on the circumstances, the adolescent could be friendly or unfriendly with you.
- Once an adolescent finds out about his or her HIV status, disclosure, safer sex, and family planning become pressing and sometimes challenging counselling issues, requiring communication approaches tailored to the specific needs of adolescents.
- Remember that ALHIV may only volunteer information about the health problem that seems most important to them but they may have many other problems and concerns. Healthcare workers should do a full assessment of the adolescent's behaviours and environment, in order to avoid missing other existing problems.
- Even with lots of training and practise, healthcare workers may find it challenging to discuss sensitive issues, like sex, disclosure and adherence to care and treatment with ALHIV.
- In order to address some of the communication challenges you will encounter, it is important to be self-aware and to discuss your thoughts and feelings about difficult situations with other colleagues or members of the multidisciplinary team.
- Even with training, healthcare workers will not be able to perfectly address all of the communication challenges that may arise with adolescent clients. It is important to remember that even the most experienced counsellors make mistakes and that you will get better with practice and over time.

## **Communication Challenges with Adolescents<sup>6</sup>**

### **Silence:**

- Silence can be a sign of shyness, embarrassment, anger, or anxiety.

***What the healthcare worker can do:***

- If it occurs at the beginning of a session, the healthcare worker can say, *“I realise it’s hard for you to talk. Talking to someone you don’t know can be scary. Many people are scared to share their feelings.”*

### **Anger:**

#### **What the healthcare worker can do:**

- Say, *“You seem angry, it’s OK to be angry, but would you like to talk about it?”* Or, if the healthcare worker thinks he or she knows why the client is angry, he or she can say something like: *“Sometimes when someone comes to see me against his or her will and doesn’t want to be here, it is difficult to speak. Is that what is going on?”*

### **Shyness:**

- Adolescents may not volunteer information about a health problem or a concern because they are not comfortable with the healthcare worker or the situation.

#### **What the healthcare worker can do:**

- Legitimise the feeling by saying, *“I would feel the same way in your place. I understand that it’s not easy to talk to a person you have just met.”*
- Use books, brochures or posters to encourage discussion or refer to a story or anecdote so the adolescent can talk about others rather than him or herself (see “Activities to promote expression with younger adolescents:” on page 17). Some adolescents simply need time to become comfortable with someone new.
- If the adolescent cannot or will not talk, the healthcare worker should propose another meeting.

### **Crying:**

#### **What the healthcare worker can do:**

- Try to evaluate what provoked the tears and assess if it makes sense in the given situation.
- If the client is crying to relieve tension, the healthcare worker can give the adolescent permission to express his or her feelings by saying, *“It’s okay to cry since it’s the normal thing to do when you’re sad.”*
- If the client is using crying as manipulation, the healthcare worker can say, *“Although I’m sorry you feel sad, it’s good to express your feelings.”*
- The healthcare worker should allow him or her to freely express emotions and not try to stop the feeling or belittle its importance.

### **Threat of suicide:**

#### **What the healthcare worker can do:**

- Take all suicide threats very seriously! Refer the adolescent to a qualified counsellor, psychiatrist or psychologist, and accompany him or her to the appointment. Work together with relevant members of the multidisciplinary care team to form an appropriate plan of action.

## **Refusal of help:**

### ***What the healthcare worker can do:***

- Discreetly try to find out why the adolescent feels this way. If the underlying feeling is anger, he or she may want to refer to some of the suggestions under “Anger:” on page 35.
- If the client has been sent against his or her will, the healthcare worker can say, *“I understand how you feel. I’m not sure I can help you, but maybe we could talk for a minute and see what happens.”*

## **Need to talk:**

### ***What the healthcare worker can do:***

- Challenges in counselling may also include a situation where the client is very vocal and wants an outlet to express other concerns that may not be directly related to the immediate counselling need as perceived by the healthcare worker. In this situation, the healthcare worker should give the client the opportunity to express his or her needs and concerns. The healthcare worker should then summarise the discussion thus far and identify the key issues that need to be discussed further today. This then sets the agenda for the rest of the meeting and gives the healthcare worker permission to pull the session back on track if the client starts discussing tangential issues.
- If the healthcare worker cannot help the client, he or she should listen to the client’s concerns (using the listening and learning skills), but clarify that he or she will have to refer the client to another professional for assistance. When appropriate, the healthcare worker should direct the client to someone who can help with the problem. The healthcare worker may say, *“I can see that you are really concerned about this problem. I wish that I could do something to help you. Have you discussed this with . . .”*
- Sometimes the key issue from the healthcare worker’s perspective is simply not enough time to devote to a particularly needy or talkative client. In this case, the healthcare worker should, about half way through the session, summarise the session so far, identifying the key points that require further discussion. Assuming the client agrees that the summary is accurate, the healthcare worker then tries to prioritise the client’s issues, suggesting that they talk about the first 2 or 3 issues in the time remaining today and that the other issues will be tackled at the next session. Assuming the client agrees with this listing of priorities, the healthcare worker then makes a note of the agenda items for the next session so they are not forgotten.

## **Talking about sex and sexuality:**

- ALHIV do not lose their desire to have sex and children. Communicating with ALHIV about sexuality can be challenging because it is a sensitive topic about which adolescents often feel emotional, defensive, and insecure.

**What the healthcare worker can do:**

- Consider the adolescent's age, understanding of HIV (the healthcare worker may ask "*What do you know about HIV?*") and of other sexual and reproductive health in general.
- Show patience and understanding of the difficulty adolescents have in talking about sexual and reproductive health issues.
- Be accepting of sexual orientation.
- Assure privacy and confidentiality.
- Use third-person questions: *Do your friends have boyfriends? How about you?*
- Respect the adolescent and his or her feelings, choices, and decisions.
- Be direct. Use clear language that is not too technical, complex or above ability to understand. Candidly discuss transmission of HIV to partners, correct condom use, and safer sex practices (for example, reduction of partners, safer ways of giving sexual pleasure): *What do you know about condoms?*
- See Module 10 for more information about Sexual and Reproductive Health.

**Talking about disclosure:**

- In adolescents who acquired HIV behaviourally, disclosure of HIV status to parents or others who can give support can be a challenge. Ideally, the adolescent will have the support of a parent or a guardian. Often, however, young people do not want their parents or caregivers to know about the medical consultation or its outcome.

**What the healthcare worker can do:**

- Discuss the value of disclosure, as a way to build a support network. At the same time, the healthcare worker should respect the young person's wishes, views, and confidentiality, should he or she not want family involvement.
- Volunteer to role play the disclosure scenario. The healthcare worker should first take the role of the adolescent client (so that the client can hear how the healthcare worker discloses). Then, the client should practise disclosing and the healthcare worker takes the role of the parent or friend (to whom the client is disclosing).
- Offer to meet with the caregiver either with or without the client.
- Identify sources of support for the client.
- See Module 7 for more information on supporting the disclosure process.

**Talking about adherence to care and treatment:**

- After a certain period, adherence may decrease, or the patient may experience side-effects or develop a toxic reaction, become resistant or suffer treatment failure. Treatment change may be required. The caregiver and adolescent need intensified support in any of these circumstances. Re-motivation is required.

***What the healthcare worker can do:***

- Ensure an open and trusting relationship with the client.
- Maintain a non-judgemental attitude to encourage the client to discuss any problems.
- Give ongoing encouragement and re-motivation, despite any adherence challenges.
- Refer the client to a support group, which can provide emotional, practical and problem-solving support from others who face similar adherence challenges.
- Ensure ongoing and regular contact with the adolescent and caregiver to help with any adherence challenges that may arise.
- See Module 8 for more information on adherence.

**Concern about confidentiality:*****What the healthcare worker can do:***

- In order for clients to trust healthcare workers with their feelings and problems, it is important for them to know that anything they say will be kept confidential. This means that members of the multidisciplinary care team will not tell other people any information about the client, including what the client says or that the client is living with HIV.
- Confidentiality is especially important for adolescents and in HIV programmes because of the stigma surrounding HIV and discrimination against ALHIV in the home, at work, at school, and in the community.

**To avoid communication challenges, healthcare workers should be aware of the following:**

- Involve adolescents in their care! Of course, their involvement should be appropriate to their interest and developmental stage.
- Assess the adolescent's emotional and developmental level (including level of understanding, capacity to express him/herself, and capacity for self-care) at every visit. This will help to ensure that expectations of the adolescent are appropriate.
- Keep in mind the changing capacities of the adolescent. With very young adolescents, the focus of counselling is generally on the caregiver. The older the adolescent, the better the adolescent's understanding and ability to express him or herself. However, because of differences between adolescents, counselling must always be adapted to the needs of the particular adolescent.
- Find out what the adolescent knows and be guided by the questions he or she asks.
- Listen to ALHIV, reflect their feelings, offer empathy, and show that you care about what they are going through. ALHIV, especially after learning about their diagnosis, might be angry, depressed, or afraid. They might feel betrayed or refuse to accept the diagnosis.
- Encourage questions to check understanding.
- Be aware of the adolescent's attention span. (A younger adolescent will lose interest more quickly than an older adolescent.)

- Watch the adolescent’s body language to determine whether he or she is taking in the information (for example, fidgeting, slumping, changing the subject, falling asleep.) If the adolescent is inattentive, stop and try again at a later stage.



### Trainer Instructions

Slides 59-62

**Step 5:** Lead participants through Exercise 3, which provides an opportunity to discuss how to overcome some communication challenges with adolescents.

### Exercise 3: Overcoming Communication Challenges: Large group discussion using case studies

<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To bring together information discussed in Session 4.3</li> <li>• To give participants an opportunity to problem solve and discuss strategies to overcome communication challenges with adolescent clients</li> </ul>
<b>Duration</b>	30 minutes
<b>Advance Preparation</b>	<ul style="list-style-type: none"> <li>• None for this exercise</li> </ul>
<b>Introduction</b>	Refer participants to the case study in their Participant Manuals.
<b>Activities</b>	<p><b>Large group discussion, with optional role play</b></p> <ol style="list-style-type: none"> <li>1. Ask participants to review the case studies in their Participant Manual.</li> <li>2. Facilitate discussion by asking the following questions about each case study and record responses on a flip chart: <ul style="list-style-type: none"> <li>• <i>What kinds of communication challenges do you think you would encounter with this client?</i></li> <li>• <i>How would you overcome them?</i></li> </ul> </li> <li>3. If there is sufficient time, ask 2 or 3 participants to role play one of the case studies in front of the large group. Ask for general comments and then ask about what issues came up for the participants during the scenario.</li> <li>4. (optional) Encourage participation from the adolescent co-trainer, who can act as the adolescent client in the role plays.</li> </ol>
<b>Debriefing</b>	<ul style="list-style-type: none"> <li>• Summarise the session by noting that adolescent clients — like adult clients — can be friendly, unfriendly, anxious and afraid, talkative and/or very reluctant to discuss sensitive issues.</li> <li>• As healthcare workers, we can be equipped to deal with some of these communication challenges by being aware of our own communication style, managing the ways we respond to the client, and continuing to discuss</li> </ul>

our thoughts and feelings with other colleagues.

### **Exercise 3: Overcoming Communication Challenges: Large group discussion using case studies**

#### **Case Study 1:**

Francis, a 14-year-old boy, meets with you for the first time after testing positive for HIV. He seems very angry and irritated. When you ask him how he is feeling, he pauses for long time, then rolls his eyes and finally tells you, in an annoyed tone, that the test must be wrong because he has only had sex with 2 people in his whole life and they were very healthy and not “bad girls.” How do you proceed?

#### **Key points for trainers: Francis**

- As Francis is able to articulate what he is angry about, first address his assumption about the inaccuracy of the HIV test (HIV antibody tests are 99% accurate). Offer to re-test him.
- Note that people with HIV are not “bad girls” or “bad boys”, maybe they’ve experienced misfortune, but they are not bad. Although his 2 girlfriends were not bad, it is quite likely that one of them had HIV. It is quite likely that she did not know it.
- If he still seems angry, use techniques discussed on page 35, under “Anger:”.

#### **Case Study 2:**

Nora is 18-years-old and has been living with HIV and on ART for many years. She just found out that she is pregnant. She is very upset and can’t stop crying. How do you proceed?

#### **Key points for trainers: Nora**

- See section entitled “Crying:” on page 35.
- Use listening and learning skills, especially empathy, identifying and naming her particular emotion as you observe it (sad, scared, angry). Encourage her to explain why she feels this way.
- Discuss her future, including her options.
- Refer her as appropriate (ANC, PMTCT, counselling on safe abortion, etc.)

#### **Case Study 3:**

Vincent is a 12-year-old boy who acquired HIV through mother-to-child transmission. He is brought to the clinic by his Auntie, because he has not been taking his ARVs. Auntie would like you to convince him to take his medicines and “stop his bad behaviour.” When you sit down and talk to Vincent, he remains completely silent and will not respond to your questions. How do you proceed?

### Key points for trainers: Vincent

- First you need to try to pierce the silence, see page 34 “Silence:”.
- Then you need to try to identify the underlying feeling that encouraged him to use silence, is he angry at his Auntie? Is he angry at you? Is he upset about having to take these mediations day in and day out? Or maybe he’s upset because he did poorly on his maths test early today. Use listening and learning skills to encourage him to talk. Once you think you’ve identified the underlying emotion, name it: “*Vincent, to me you seem angry because \_\_\_\_\_. Can you tell me if you think this is accurate?*”
- Once you can get him to identify the underlying issues, you can then discuss a plan.
- You will eventually need to meet with Vincent and his Auntie together. With Vincent’s permission you may want to advocate on his behalf to encourage the Auntie to deal with Vincent in a more appropriate and positive manner.



#### Trainer Instructions

**Step 6:** Allow 5 minutes for questions and answers on this session.



#### Trainer Instructions

Slides 63-66

**Step 7:** Ask participants what they think the key points of the module are. What information will they take away from this module?

**Step 8:** Summarise the key points of the module using participant feedback and the content below.

**Step 9:** Ask if there are any questions or clarifications.



#### **Module 4: Key Points**

- Establishing a comfortable and open relationship is the foundation for communication and education, and increases the chances that the client will return for treatment.
- When asked by healthcare workers about sensitive issues, like sexual activity, adolescents may be reluctant or embarrassed to disclose information for fear of being scolded or mocked.
- When communicating with adolescent clients, it is important to be respectful, ensure privacy, maintain confidentiality, be honest, use language that they understand, and be open to their ideas and choices, even if they are not the ones you would have wanted them to make.
- Some communication and counselling tips for adolescents are: starting the conversation by building rapport and non-threatening issues, asking indirect questions about a third person, and trying to reduce stigma around an issue by normalising it. Younger adolescents will sometimes require a more activity-based approach to counselling than older adolescents, such as storytelling, games, reading, and art.
- Good communication is the key component to effective counselling. These are the 7 key listening and learning skills healthcare workers should always use:
  - Use helpful non-verbal communication.
  - Actively listen and show interest in the client.
  - Ask open-ended questions.
  - Reflect back what the client is saying.
  - Empathize — show that you understand how the client feels.
  - Avoid words that sound judging.
  - Help the client set goals and summarise each counselling session.
- The healthcare worker's strategy for a particular counselling session is determined by the adolescent's needs as well as his or her behaviour (silent or talkative), mood (sad, angry or happy), and attitude (I love being here, I hate having HIV).

## **Appendix 4A: Common Counselling Mistakes<sup>7</sup>**

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**The “Listening and Learning Skills” are easy to learn but difficult to apply. Some common mistakes include:**

- Not allowing enough time for counselling, making it hard for the client to take in all the information and react.
- Conducting counselling in a non-private space, such as in a corridor or waiting area or allowing interruptions during the counselling session.
- Controlling the discussion, instead allowing the client to control the session by asking questions and expressing their feelings and needs.
- Judging the client — making statements that show that the client does not meet the healthcare worker’s standards.
- Preaching to a client — telling clients how they should behave or lead their lives, for example, saying: *“you never should have trusted that guy, now you have created a big problem for yourself”*.
- Labelling a client instead of finding out their individual motivations, fears or anxieties.
- Reassuring a client without even knowing her or his health status — for example, telling a client, *“you have nothing to worry about”*.
- Not accepting the client’s feelings — saying *“you shouldn’t be upset about that”*.
- Advising, before the client has collected enough information or taken enough time to arrive at a personal solution.
- Interrogating — asking accusatory questions. Questions that start with *“why...?”* can sound accusatory, though the tone is important, as “why” questions may also be a way of getting an open-ended response.
- Encouraging dependence — increasing the client’s need for the healthcare worker’s guidance.
- Persuading or coaxing — trying to get the client to accept new behaviour by flattery or fakery. *“I know you are a good girl and you will take your ARVs like I have told you.”*

## Appendix 4B: General Tips on How to Talk With Adolescents<sup>8</sup>

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This section presents general guidelines on interacting with adolescents, either when providing testing or ongoing care and treatment. Establishing a comfortable and open relationship (using the listening and learning skills discussed in Session 4.2) is the foundation for communication, and increases the chances that a client (and his or her caregivers) will return.

The age and developmental stage of the adolescent is critical to the way in which the healthcare worker communicates with him or her. Some basic principles about working with adolescents include:

- Make the young person feel comfortable from the beginning; create a comfortable environment by encouraging the adolescent to talk about general things that interest him or her before going on to discuss specific issues in their personal lives. (*for example, Did you hear about the football match last night? How is school going? I like the blouse you're wearing, did you sew that as well?*)
- Engage and take an interest in the adolescent and not just in her or his physical condition.
- Meet the young person at her or his level; this might mean using creative methods to help adolescents, especially younger ones, to feel comfortable and express their feelings as well as making the information more concrete.
- Maintain eye contact.
- Do not ask too many questions.
- Listen attentively.
- Use language that is developmentally appropriate. Be direct. Use clear language that is not too technical, complex or above ability to understand.
- Avoid false reassurances and do not impose your personal beliefs on the situation.
- Younger adolescents will need the presence of a trusted adult to feel secure. Try involving caregivers and other family members in the counselling process.
- Explain confidentiality; note that there are some situations in which it may be necessary to breach confidentiality.
- Act appropriately and with authority without being an authoritarian.
- Use an interactive, participatory style of communicating. Allow time and opportunity for the adolescent to educate and inform you about his or her ideas and decisions.

## Appendix 4C: Basic Counselling Guidance for ALHIV

The previous appendix provided general guidance for healthcare workers when speaking with ALHIV. This appendix provides suggested conversational cues or prompts for introducing some of the core topics related to HIV care and treatment. This appendix is meant to be a simplified framework outlining main discussion points around care and treatment — not a comprehensive counselling script.

<b>Counselling an adolescent living with HIV, Ages 10–12</b>	
<b>Guidance</b>	
<ul style="list-style-type: none"> <li>• Give realistic information about health status.</li> <li>• At this age, depending on his or her developmental level, it may be appropriate to begin discussions about HIV.</li> <li>• Emphasize that people with HIV can live meaningful lives and have normal relationships.</li> <li>• Help the adolescent deal with possible stigma.</li> </ul>	
<b>Objectives</b>	<b>Script</b>
<b>Tell the client that you are here to address his or her specific questions and concerns.</b>	<p>I want to talk with you about any questions you have about your HIV result. OR</p> <p>I want to talk with you about any questions you have about your health and clinic visits. (Use the term “HIV” only if the adolescent knows his or her diagnosis; otherwise substitute a word such as “a germ” or “your health” for “HIV” and continue working with caregivers on disclosure. If the adolescent does not know his or her diagnosis, the following script will need to be adapted, or covered over a span of many visits.)</p>
<b>Talk about HIV in age-appropriate terms.</b>	HIV is a sickness that lives in your blood and makes it easier for you to get other sicknesses. That means that you will get sick very often if you don’t take your medicines and take them correctly. You should know that even if you have HIV, you can still grow up to live a good life.
<b>Discuss ART and adherence.</b>	It is important for you to take your medicine every day and not skip any doses, even if you don’t feel like taking them. These medicines will help you to stay healthier. Are you having any problems remembering to take or problems taking your medicines?
<b>Talk about ways to stay healthy.</b>	Knowing that you have HIV will let you take control of your health. To stay healthy you should always take your medicines. You can also stay healthy by eating healthy foods, exercising and getting enough sleep.
<b>Discuss confidentiality. Encourage the adolescent to decide with his or her caregivers who it is okay to talk to about HIV.</b>	While knowing your HIV status is necessary for taking good care of yourself, it is not something you have to share with everyone. Your test results are confidential. That means that they are only shared with doctors and nurses who help to take care of you. You and your caregivers, together, can decide who else you feel comfortable talking to about your HIV status.
<b>Ask about HIV-related discrimination.</b>	Some people have the wrong information about HIV and might treat you differently if they think you have HIV because they just don’t know any better.

	Has this happened to you? Some of the things you can do are: talk to someone you trust who can help you to manage the bad feelings; know that you have friends and family who love and care for you; and understand that HIV is just a sickness. Having it does not make you a bad or different person. You just have to take care of your health. You will be able to live a healthy life, just like others.
<b>Provide referrals.</b>	There are doctors who are experts in taking care of people just like you. There are also support groups and services in the community, such as _____, _____ and _____. Our referral team can help you get in touch with these services.
<b>Comfort the adolescent.</b>	There are a lot of ways you can stay healthy and we are here to help you.
<b>Address any questions and concerns.</b>	What questions do you have? If you think of any questions later on, I am available to answer them. Let's talk about how you can contact me if you have any more questions.

### Counselling an adolescent living with HIV, Ages 13–19

<b>Guidance</b>	
<ul style="list-style-type: none"> <li>• Give realistic information about health status; answer all questions.</li> <li>• The adolescent should know her or his HIV status by this stage. Waiting to disclose makes learning about HIV much more difficult for the adolescent to accept.</li> <li>• Emphasize that people with HIV can live meaningful lives and have normal relationships.</li> <li>• Help the adolescent deal with possible stigma.</li> <li>• Include prevention information in pre- and post-test counselling.</li> </ul>	
<b>Objectives</b>	<b>Script</b>
<b>Tell the client that you are here to address his or her specific questions and concerns.</b>	I want to talk with you about any questions you have about your health and clinic visits.
<b>Talk about HIV in age-appropriate terms.</b>	HIV is a sickness that lives in your blood and makes it easier for you to get other sicknesses. That means that you will get sick very often if you don't take your daily medicines and take them correctly. You should know that even if you have HIV, you can still have a good life, even get married if you want to.
<b>Discuss ART and adherence.</b>	It is important for you to take your medicine every day and not skip any doses, even if you don't feel like taking them. These medicines will help you to stay healthier. What are you doing now to remember to take your medicines every day? How many times have you forgotten to take your medicines in the past three days?  If appropriate: Tell me a bit more about why you missed some doses of your medicine? What are your ideas to improve adherence (that is, to remember to take your medicine every day at about the right time)?
<b>Talk about ways to stay healthy.</b>	Knowing that you have HIV will let you take control of your health. To stay healthy you should always take your medicines. You can also stay healthy by eating healthy foods, exercising and getting enough sleep.
<b>Discuss confidentiality.</b>	While knowing your HIV status is necessary for taking

<p><b>Encourage the adolescent to decide with his or her caregivers who it is okay to talk to about HIV.</b></p>	<p>good care of yourself, it is not something you have to share with everyone. Your test results are confidential. That means that they are only shared with doctors and nurses who help to take care of you. You and your caregiver, together, can decide who else you feel comfortable talking to about your HIV status.</p>
<p><b>Ask about HIV-related discrimination.</b></p>	<p>Some people have the wrong information about HIV and might treat you differently if they know you have HIV because they just don't know any better. You should be ready in case you run into someone like this.</p> <p>Has this happened to you? Some of the things you can do are: talk to someone you trust who can help you to manage your reaction; know that you have friends and family who love and care for you; and understand that HIV is just a sickness. Having it does not make you a bad or different person. You just have to take care of your health. You will be able to live a healthy life, just like others.</p>
<p><b>Provide referrals.</b></p>	<p>There are doctors who are experts in taking care of young people with HIV. There are also support groups and services in the community, such as _____, _____ and _____. Our referral team can help you get in touch with these services.</p>
<p><b>Talk about the responsibility to protect others.</b></p> <p><b>When age-appropriate, talk about safer sex.</b></p>	<p>Now that you know your HIV status, you have the power to stay healthy. It is also your responsibility to prevent the spread of HIV. HIV can spread through blood, breast milk, pregnancy and unprotected sex (sex without a condom).</p> <p><b>If you are not yet having sex</b>, it is important that you stay abstinent until you are at an age when you are ready for what may happen if you have sex, for example, getting pregnant or getting a sexually transmitted infection.</p> <p>You can pass on HIV to your partner if you have sex without a condom. That means that you should always use a condom when you have sex. This will also help prevent against unwanted pregnancies. Having sex without a condom is the most common way that HIV is spread. If you are having sex, it is important that you stay with only one partner and talk to your partner about being only with you.</p>
<p><b>Comfort the adolescent.</b></p> <p><b>Address any questions and concerns.</b></p>	<p>There are a lot of ways you can stay healthy and we are here to help you.</p> <p>What questions do you have? If you think of any questions later on, I am available to answer them. Let's talk about how you can contact me if you have any more questions.</p>

Adapted from: Zambia MoH. 2010. National Training Package on Provider-Initiated Paediatric HIV Testing & Counselling in Zambia.

## Appendix 4D: Listening and Learning Skills Checklist

Listening and Learning Skills Checklist		
Skill	Specific Strategies, Statements, Behaviours	(√)
<b>SKILL 1: Use helpful non-verbal communication</b>	• Make eye contact	
	• Face the person (sit next to him or her) and be relaxed and open with posture	
	• Use good body language (nod, lean forward, etc.)	
	• Smile	
	• Do not look at your watch, the clock or anything other than the client	
	• Do not write during the session	
	• Other (specify)	
<b>SKILL 2: Actively listen and show interest in your client</b>	• Use gestures that show interest (nod and smile), use encouraging responses (such as “yes,” “okay” and “mm-hmm”).	
	• Clarify to prevent misunderstanding	
	• Summarise to review key points at any time during the session	
	• Other (specify)	
<b>SKILL 3: Ask open-ended questions</b>	• Use open-ended questions to get more information	
	• Other (specify)	
<b>SKILL 4: Reflect back what your client is saying</b>	• Reflect back or paraphrase	
	• Encourage client to discuss further (“Let’s talk about that some more”)	
	• Other (specify)	
<b>SKILL 5: Show empathy, not sympathy</b>	• Demonstrate empathy: show an understanding of how the client feels by naming the emotion expressed	
	• Avoid sympathy	
	• Other (specify)	
<b>SKILL 6: Avoid judging words</b>	• Avoid judging words such as “bad,” “proper,” “right,” “wrong,” etc.	
	• Use words that build confidence and give support (for example, praise what a client is doing right)	
	• Other (specify)	
<b>SKILL 7: Help your client set goals and summarise each counselling session</b>	• Work with the client to come up with realistic “next steps”	
	• Summarise the main points of the counselling session	
	• Set next appointment date; discuss availability of clinic services outside of clinic visits	

Adapted from: World Health Organization. 2008. Prevention of Mother-to-Child Transmission of HIV Generic Training Package. Available at: [http://www.womenchildrenhiv.org/pdf/p03-pi/pi-60-00/Intro\\_PM\\_2-05.pdf](http://www.womenchildrenhiv.org/pdf/p03-pi/pi-60-00/Intro_PM_2-05.pdf)

## References and Resources

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<sup>1</sup> Senderowitz, J., Solter, C., & Hainsworth, G. 2004. *Comprehensive Reproductive Health and Family Planning Training Curriculum. 16: Reproductive Health Services for Adolescents*. Watertown, MA: Pathfinder International.

<sup>2</sup> Senderowitz, J., Solter, C., & Hainsworth, G. 2004. *Comprehensive Reproductive Health and Family Planning Training Curriculum. 16: Reproductive Health Services for Adolescents*. Watertown, MA: Pathfinder International.

<sup>3</sup> Zambia MoH. 2010. *National Training Package on Paediatric Provider-initiated HIV Testing & Counselling in Zambia*.

<sup>4</sup> World Health Organization. 2008. *Prevention of Mother-to-Child Transmission of HIV Generic Training Package*.

<sup>5</sup> ICAP. 2010. *Improving Retention, Adherence, and Psychosocial Support within PMTCT Services, Implementation Workshop Curriculum for Health Workers, Trainer's Manual*. Available at: <http://www.columbia-icap.org/resources/pmtct/index.html>

<sup>6</sup> Senderowitz, J., Solter, C., & Hainsworth, G. 2004. *Comprehensive Reproductive Health and Family Planning Training Curriculum. 16: Reproductive Health Services for Adolescents*. Watertown, MA: Pathfinder International.

<sup>7</sup> World Health Organization. 2008. *Prevention of Mother-to-Child Transmission of HIV Generic Training Package*.

<sup>8</sup> REPSSI. 2008. *Mainstreaming Psychological Care and Support within Paediatric HIV and AIDS Treatment*.



# Module 5 Providing Psychosocial Support Services for Adolescents



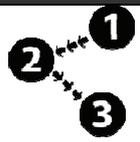
**Total Module Time:** 215 minutes (3 hours, 35 minutes)

## Learning Objectives

**After completing this Module, participants will be able to:**

- List common psychosocial needs of adolescent clients.
- Conduct a psychosocial assessment with adolescent clients and caregivers, to better determine their specific psychosocial needs and types of support required.
- Provide ongoing, age-appropriate psychosocial support services, including referrals, for adolescents and caregivers.
- Identify strategies to support adolescent clients and caregivers to deal with stigma and discrimination.
- Provide psychosocial support services, including referrals, to most-at-risk ALHIV.
- Understand the importance of peer support in meeting adolescents' psychosocial support needs.

### Methodologies



- Interactive trainer presentation
- Large group discussion
- Brainstorming
- Case studies
- Role play
- Small group work

### Materials Needed



- Slide set for Module 5
- Flipchart and markers
- Tape or Bostik
- Participants should have their Participant Manuals. The Participant Manual contains background technical content and information for the exercises.

### References and Resources



- WHO. 2010. *IMAI One-day orientation on Adolescents Living with HIV, Facilitator Guide*, Geneva, WHO Press.
- Working Group, U.S. Agency for International Development, the Joint United Nations Programme on



	<p>HIV/AIDS (UNAIDS) Inter-Agency Task Team on HIV and Young People, and FHI. 2010. <i>Young People Most at Risk of HIV: A Meeting Report and Discussion Paper from the Interagency Youth</i>. Research Triangle Park, NC: FHI, 2010.</p> <ul style="list-style-type: none"><li>• Republic Of Zambia, Ministry Of Health. 2010. <i>National Training Package on Provider-initiated Paediatric HIV Testing &amp; Counselling in Zambia</i>.</li></ul>
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**Advance Preparation**



- Read through the entire module and ensure that all trainers are prepared and comfortable with the content and methodologies.
- Review the appendices in this module ahead of time and prepare to incorporate them into the discussion.
- Exercise 1 requires advance preparation. Review ahead of time.

### **Session 5.1: The Psychosocial Needs of Adolescent Clients**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation and large group discussion	20 minutes
Questions and answers	5 minutes
Total Session Time	25 minutes

### **Session 5.2: Assessing Psychosocial Support Needs**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation and large group discussion	20 minutes
Exercise 1: Assessing Psychosocial Support Needs: Case studies and large group discussion	45 minutes
Interactive trainer presentation and large group discussion	25 minutes
Questions and answers	5 minutes
Total Session Time	95 minutes

### **Session 5.3: Providing Psychosocial Support Services for the Most-At-Risk Adolescent**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation and large group discussion	25 minutes
Exercise 2: Psychosocial Support to the Most-at-Risk Adolescents: Large group discussion using case studies	30 minutes
Questions and answers	5 minutes
Total Session Time	60 minutes

### **Session 5.4: Peer Support in Psychosocial Services for Adolescents**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation and large group discussion	20 minutes
Questions and answers	5 minutes
Review of Key Points	10 minutes
Total Session Time	35 minutes

## Session 5.1

# The Psychosocial Needs of Adolescent Clients



**Total Session Time:** 25 minutes



### Trainer Instructions

Slides 1-5

**Step 1:** Begin by reviewing the Module 5 learning objectives and the session objective, listed below.

**Step 2:** Ask participants if there are any questions before moving on.

### Session Objective

**After completing this session, participants will be able to:**

- List common psychosocial needs of adolescent clients.



### Trainer Instructions

Slide 6

**Step 3:** Explain that providing psychosocial support means helping with problems on the inside (psycho) and the outside (social).

Ask participants to brainstorm the definitions of **psychosocial**, **psychosocial support**, and **psychosocial well-being**, and fill in content using the content below as needed.

Debrief by explaining that the provision of psychosocial support is about helping people develop or re-discover the resources or tools they use to solve their own problems. Psychosocial support can assist people in making informed decisions, cope better with illness, deal more effectively with discrimination, and improve the quality of their lives.



### Make These Points

- Psychosocial support addresses the ongoing psychological and social problems of the client, their partners, families, and caregivers.
- Psychosocial support can help adolescents and their caregivers to

understand and deal with difficult circumstances, overcome challenges, and develop positive coping skills.

- Psychosocial support can help an adolescent achieve psychosocial well-being and/or reduce adverse outcomes to ALHIV.

## Overview of Psychosocial Support

### Definition of psychosocial support and well-being:

- **Psycho** refers to the mind and soul of a person. This involves internal aspects such as feelings, thoughts, beliefs, attitudes, and values.
- **Social** refers to a person's external relationships and environment. This includes interactions with others, social attitudes, and values (culture) and social influences of family, peers, school, and community.
- **Psychosocial support** addresses the ongoing emotional, social, and spiritual concerns and needs of people living with HIV, their partners, and their caregivers.
- **Psychosocial well-being** is when these internal and external needs are met and a person is physically, mentally, and socially healthy.



### Trainer Instructions

Slides 7-13

#### Step 4:

Explain that HIV infection affects all dimensions of a person's life: physical, psychological, social, and spiritual. Since there are many ways in which adolescents are different from children and adults, their psychosocial needs are also unique — requiring a tailored response from the health system.

Ask the group the following questions to guide discussion (record responses on a flipchart):

- *Why do you think that adolescents have special or unique psychosocial needs?*
- *What are some common psychosocial needs of adolescent clients?*
- *How are the psychosocial needs of younger adolescents different from older adolescents?*
- *How do you think the psychosocial needs of perinatally infected adolescents differ from those adolescents who have been recently infected?*
- *Why is providing psychosocial support important to ALHIV and their caregivers?*



### **Make These Points**

- HIV affects all parts of a person's life: physical, mental, social, and spiritual.
- Psychosocial needs of adolescents are different than adults or children, due to the major physical, emotional, and mental changes that occur during this stage of development.
- Adolescents have many unique psychosocial needs that require consideration, such as need for acceptance and approval from their peers, a desire to be “normal” and fit in, need for a sense of belonging in the world, and support around the desire to have relationships and children.
- An adolescent's psychosocial needs change over time and should be given consideration by the healthcare worker at every clinic visit.
- Psychosocial support can help adolescent clients and their caregivers gain confidence in themselves and their skills, such as dealing with long-term illness, dealing with stigma or discrimination, dealing with taking medications every day, caring for an HIV-exposed or HIV-infected child, etc.
- Psychosocial support can be used to enhance an adolescent's support networks through helping to maintain, enhance and/or repair ALHIV's connections to caregivers or other extended family members.

## **Psychosocial Support Needs of ALHIV**

All adolescents have unique psychosocial needs, which are different than those of children and adults, because adolescence is a unique stage of life that is characterised by:

- Significant physical, emotional, and mental changes
- Risk taking behaviour and experimentation
- Sexual desires, expression, and experimentation
- Insecurity/confusion
- Anxiety
- Reactive emotions
- Criticism of caregivers or elders
- Focus on body image
- Sense of immortality
- Need to challenge authority figures while nonetheless still needing their support

### **ALHIV have additional psychosocial needs, which may include:**

- Support in understanding and coming to terms with their own HIV-status and the effect it has on their own and their family's lives.
- Support in understanding and coming to terms with family members' HIV status, especially in the case of perinatally infected youth.
- Support with grieving the loss of parents and/or siblings.

- Support with the increased responsibilities at home and/or a need to generate income as a result of having a deceased or an ill parent(s)
- Support with responsibility for the care of younger siblings.
- Help to manage problems with school fees or having time to attend school, etc.
- Support with the disclosure process.
- Help coping with their diagnosis.
- Help maintaining connections to important adults including immediate family, extended family, adults who can serve as mentors.
- Support with discussing sexual and reproductive health issues, including disclosure to partners, safer sex or delaying sexual debut.
- Discussion of views about taking medication when they may not be feeling sick and they just want to fit in and be “normal”.
- Help with developing self-esteem and confidence.
- Sense of belonging, acceptance or fitting in with peers, community, etc.
- Strategies to disclose their HIV-status to their peers, family and community members.
- Strategies to deal with stigma and discrimination.
- Strategies to encourage their partners and family members to test and, if appropriate, enrol into care and treatment programmes.
- Access to education and training — and work opportunities once they have completed school/training.
- Access to higher education.
- Access to social welfare services.
- Spiritual support and referrals to spiritual counselling.
- Knowledge about their legal issues and rights.
- Support around planning for the future and issues such as having children.
- Support for mental health, including strategies for managing anxiety and depression (see Module 6 for more information about Mental Health and ALHIV).
- Substance abuse management.
- Strategies to best utilise support networks.
- Support for their anxiety about having children; or for others, support to delay pregnancy until they are old enough to accept the responsibility of raising a child.

**Providing psychosocial support is important for ALHIV and their caregivers because:**

- HIV affects all parts of a person's life: physical, mental, social and spiritual dimensions.
- Perinatal HIV is often associated with a series of family adversities for which emotional and material supports are needed to achieve good outcomes for adolescents.
- Relationships with parents and caregivers may become more conflicted as the adolescent tests limits and moves towards independence, resulting in disruptions that reduce the adolescent's access to needed support.

- Psychosocial support can help clients and caretakers gain confidence in themselves and their skills (dealing with long-term illness, dealing with stigma or discrimination, dealing with taking medications every day, caring for an HIV-exposed or HIV-infected child, etc.).
- Psychosocial well-being is related to better adherence to HIV care and treatment.
- Good mental health is closely linked to good physical health.
- All adolescents need support coping with normal developmental issues as well, such as wanting to feel normal and fit in with peers.
- Psychosocial support will increase clients' understanding and acceptance of all HIV comprehensive care and support services.
- Psychosocial support from healthcare workers and other members of the multidisciplinary team can help prevent ALHIV from entering most-at-risk category.



### **Trainer Instructions**

**Step 5:** Allow 5 minutes for questions and answers on this session.

## Session 5.2      Assessing Psychosocial Support Needs

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**Total Session Time:**      95 minutes (1 hour, 35 minutes)



### **Trainer Instructions** Slides 14-15

- Step 1:**      Begin by reviewing the session objectives listed below.
- Step 2:**      Ask participants if they have any questions before moving on.

### **Session Objectives**

**After completing this session, participants will be able to:**

- Conduct a psychosocial assessment with adolescent clients and caregivers, to better determine their specific psychosocial needs and types of support required.
- Identify strategies to support adolescent clients and caregivers to deal with stigma and discrimination.



### **Trainer Instructions** Slides 16-18

- Step 3:**      Explain that adolescents on their own may not be able to satisfy or meet their own needs largely due to lack of social skills, lack of information and knowledge, and lack of economic and social power. Therefore, healthcare workers play a critical role in assessing and meeting clients' psychosocial needs. While healthcare workers are not able to address all of a client's needs, there are many things that we can do to improve psychosocial well-being.
- Step 4:**      Continue by explaining that, to better determine an adolescent's psychosocial needs, a psychosocial assessment should be conducted with each client after enrolment in HIV care and treatment services. Healthcare workers may want to conduct another psychosocial assessment or revisit specific psychosocial issues when a client's situation changes in a significant way (for example, he starts secondary school, her mother dies, or she moves into a foster home). Review "Appendix 5A: Psychosocial Assessment Tool" as well as "Tips to Remember When Conducting a Psychosocial Assessment".



### **Make These Points**

- The use of tools, such as the Psychosocial Assessment Tool, can help determine what services and referrals are needed to support a client and ensure his or her psychosocial well-being. Findings from the assessment should be recorded on the assessment tool and stored in the client's file.
- A psychosocial assessment should be conducted when a client enrolls in HIV care and treatment services and again, if his or her situation changes significantly.
- To build a trusting relationship and encourage honesty, it is important for healthcare workers to be patient and have a non-judgemental and positive attitude when conducting a psychosocial assessment. Remember: our job as healthcare workers is to work WITH our clients, not against them!

## **Conducting a Psychosocial Assessment**

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### **Tips to remember during the psychosocial assessment process:**

- Emphasize that all information is confidential and private, but that healthcare workers may share some of the information with other providers in the clinic to ensure the best care for the client.
- Conduct the assessment in a space that has visual and auditory privacy.
- Involve the adolescent at all phases of the assessment process.
- Respect the dignity and worth of the adolescent at all times.
- Do not talk down to an adolescent. Use good listening and learning skills, as discussed in Session 4.2.
- Always be positive! Offer lots of encouragement and praise throughout the assessment.
- Be patient! Allow an adolescent to speak for himself/herself. Allow the client to express his or her views and describe his or her experiences.
- Respect the adolescent's coping skills and their ideas and solutions to the problem.

#### **Family-centred care versus client confidentiality**

It is important to ensure the inclusion of caregivers and other family members in care. But it is equally important that private information discussed during an individual session with an ALHIV remain confidential and is not shared with caregivers. Clients will be unwilling to discuss personal issues unless they have a guarantee of confidentiality.

- Do not judge! Make adolescents feel comfortable and not fearful that they will be punished or judged, especially if they openly discuss challenges.
- Offer to include caregivers' and/or family members' input into the assessment as needed and agreed upon by the adolescent, while simultaneously protecting the confidentiality of information.
- Keep good records. Always keep a copy of the psychosocial assessment in the client's file.



### **Trainer Instructions**

Slides 19-22

#### **Step 5:**

Continue by asking participants to reflect about what healthcare workers can do to address the psychosocial needs of ALHIV and their caregivers. Ask the following questions to facilitate discussion:

- *To ensure a client's needs are met, what should you do once you have completed a psychosocial assessment?*
- *What can you suggest to clients and caregivers to help them positively cope with challenging situations?*

#### **Step 6:**

Lastly, explain that the most effective strategy for ensuring psychosocial well-being of ALHIV is preventing adolescents from entering the situation of being on their own in the first place. Working to maintain, enhance, and repair adolescent's existing support systems and relationships with caregivers and extended family members, whenever possible, is a critical part of providing psychosocial support.

- *What do you think healthcare workers can do maintain, enhance and/or repair ALHIV's connections to caregivers or concerned family members?*



### **Make These Points**

- Healthcare workers should use the 5 "A's" (see "Table 3.1: Using the 5 "A's" during clinical visits with adolescents" in Module 3) when conducting a psychosocial assessment.
- Healthcare workers can, and should, suggest positive coping strategies to help adolescents and caregivers deal with challenges and meet their psychosocial needs.
- It is important that healthcare workers help adolescents solve problems that have led to or could lead to estrangement from their families. Except in situations of severe abuse and neglect, it is impossible to replace the advantages of remaining part of a family structure.

- Healthcare workers can, and should, suggest positive coping strategies to help adolescents and caregivers deal with challenges and meet their psychosocial needs.
- Healthcare workers can plan in advance and counsel the adolescent to help them with caregiver transitions (for example, if a mother is becoming too ill to care for her children, family counselling to reduce the likelihood of an adolescent being abandoned or running away, help with reconciliation if the adolescent is already estranged from the family, etc.).

## Overview of Coping Strategies

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**Healthcare workers should** use the 5 “A’s” when conducting a psychosocial assessment with clients: **ASSESS, ASSIST, ADVISE, AGREE** and **ARRANGE**.

- **Assess** the client’s psychosocial needs, ideally using a standardised assessment tool (see Appendix 5-A).
- **Advise** and guide, and schedule next visit.
- **Assist** — provide take-away information on the plan, provide psychosocial support and referrals, address any problems or challenges the client is facing, help the client come up with solutions and strategies that work for him/her, offer to talk to family members and caregivers about the situation if the adolescent is in agreement with this.
- **Agree** on an action plan for the situation.
- **Arrange** a follow-up appointment and arrange for attendance in support groups or group education sessions, etc.
- Refer to clinical checklist in Module 3 for more information on the 5 “A’s”.

Healthcare workers can suggest coping strategies to clients and caregivers to help them reduce stress, deal more effectively with challenges, and promote their psychosocial well-being. Coping strategies might include:

- Talk about a personal problem with someone you trust, such as a friend, family member, counsellor or Peer Educator
- Seek assistance in resolving the problems that you are having with your family/caregiver
- Join a support group
- Exercise
- Change your environment and take a walk
- Seek spiritual support
- Attend a cultural event, like traditional dancing or singing
- Join in recreational activities, like sports or youth clubs
- Return to your daily routine, like cooking or going to school
- Do something to make yourself feel useful, like helping a sibling with homework

- Seek professional help from the clinic if you are sad, depressed, anxious, etc for a long period of time (see Module 6 for more information about Mental Health and ALHIV)

Helping clients express themselves and encouraging them to tell their stories and share their problems also helps them to:

- Feel a sense of relief
- Reduce feelings of isolation
- Think more clearly about what has happened
- Feel accepted, cared, and valued by the person who listens
- Develop confidence
- Build self esteem
- Explore options or solutions to make better decisions
- Prevent bad feelings from coming out as aggressive behaviour
- Maintain needed support from family members and other adults

Lastly, healthcare workers can plan in advance and counsel the adolescent to help them with caregiver transitions (for example, if a mother is becoming too ill to care for her children, family counselling to reduce the likelihood of an adolescent being abandoned or running away, help with reconciliation if the adolescent is already estranged from the family, etc.).



### **Trainer Instructions**

Slides 23-26

#### **Step 7:**

Lead participants through Exercise 1, which gives an opportunity to discuss how to assess and address the psychosocial needs of ALHIV and their caregivers, using case studies.

**Exercise 1: Assessing Psychosocial Support Needs: Case studies and large group discussion**

<b>Purpose</b>	<ul style="list-style-type: none"> <li>To discuss the adolescent psychosocial assessment, using “Appendix 5A: Psychosocial Assessment Tool” and applying the 5 “A’s”</li> </ul>
<b>Duration</b>	45 minutes
<b>Advance Preparation</b>	<ul style="list-style-type: none"> <li>Be prepared to explain how to complete the sample Psychosocial Assessment Tool and to demonstrate how to conduct a psychosocial assessment, using this tool.</li> </ul>
<b>Introduction</b>	Explain that a client’s psychosocial well-being should be considered at every visit. A psychosocial Assessment Tool is a standardised format to determine a client’s specific psychosocial needs and support decision making.
<b>Activities</b>	<p><b>Large Group Discussion</b></p> <ol style="list-style-type: none"> <li>Ask participants to review the case studies in their Participant’s Manuals. Suggest that they refer to “Appendix 5A: Psychosocial Assessment Tool” and the 5 “A’s” in Table 3.6 in Module 3.</li> <li>Write “<b>Assess</b>”, “<b>Advise</b>”, “<b>Agree</b>”, “<b>Assist</b>”, and “<b>Arrange</b>” on flip chart paper posted in the front of the room.</li> <li>Starting with the first case study, ask the group to identify the important issues in relation to each of the 5 “A’s”, starting with “<b>Assess</b>”. Then go onto “<b>Advise</b>” and the remaining 5 “A’s” in order.</li> <li>Record key issues under each of the “A’s” on the flip chart in the front of the room.</li> <li>Move onto the 2<sup>nd</sup> case study following the same steps. If you are not conducting the optional role play, also discuss the 3<sup>rd</sup> role play following the same steps (above).</li> </ol> <p><b>Optional Role Play</b></p> <ol style="list-style-type: none"> <li>If there is sufficient time, ask 2 participants to volunteer as the “healthcare worker” and “client” and role play in front of the large group a psychosocial assessment, using the 3<sup>rd</sup> case study.</li> <li>(optional) Encourage participation from the adolescent co-trainer, who can act as the client in the role play. Ask the following questions to encourage his or her and input and participation: <ul style="list-style-type: none"> <li><i>What did the healthcare worker do to build trust and rapport with you?</i></li> <li><i>Is there anything else the healthcare worker could have suggested or done to address the client’s psychosocial needs?</i></li> </ul> </li> </ol>
<b>Debriefing</b>	<ul style="list-style-type: none"> <li>A client’s psychosocial needs change over time and</li> </ul>

	<p>should be informally assessed and considered at every visit.</p> <ul style="list-style-type: none"> <li>• The 5 “A’s” — ASSESS, ASSIST, ADVISE, AGREE and ARRANGE — are a useful tool for structuring the counselling session, so that none of the key steps are forgotten.</li> </ul>
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### **Exercise 1: Assessing Psychosocial Support Needs: Case studies and large group discussion**

#### **Case Study 1:**

You meet with a young 13-year-old girl named Lesiana whose mother has just passed away from an HIV-related infection. Lesiana is enrolled in the ART programme and generally comes to all of her appointments and adheres to her medicines. Yesterday, Lesiana missed an appointment and today, she arrives late. She tells you that she is depressed about school — she used to be ranked first in her class and now she is ranked last. She also tells you that she never feels like hanging out with her friends anymore. How do you proceed with Lesiana?

#### **Key point for trainers: Lesiana**

- **Assess:**
  - Her understanding of bereavement in light of her mother’s death
  - Her support networks to help her deal with her bereavement
  - Her understanding of what will happen to her social and home situation now that her mother has passed away
  - Her family’s understanding of who will provide for Lesiana now that her mother has died (for example living arrangements, school fees, care of younger siblings, etc); this will require consulting with family members
  - Her understanding of why she is not doing well at school
  - Adherence to her medications during this difficult time
  - Her clinical status to ensure that the cause of her depressive symptoms isn’t due to disease progression (see Module 6 for more information about assessing and managing depression and other Mental Health issues)
  - Acknowledge Lesiana’s very sad and difficult situation; praise her efforts to cope
- **Advise:**
  - Her that her bereavement is a normal response to the loss of a loved one and to a fear of what the future may hold now that her mother is no longer here.
  - Her that if she doesn’t begin to feel better over the coming months she may need help for depression
  - Her to ensure she has someone to whom she can discuss her recent losses
  - Her to consider a step-by-step plan to do well in school; make sure the plan allows Lesiana the flexibility she needs to mourn the

loss of her mother and adjust to her new social situation — maybe she will aim to study 30 minutes every night this week, but increase that to 1 hour next week and then back up to 2+ hours by the end of the month.

- Her to come to the clinic with a family member(s) to discuss future plans with regard to living arrangements, school, household tasks, care of younger siblings and other practical matters
- Counsel on the importance of adhering to her ART regimen as well as her clinic visit schedule, for the sake of her long term health
- Agree:
  - That she will adhere to her ART regimen, and attend every clinic visit
  - That she will adhere to her own plan to get her school grades up
  - That she will discuss her social situation with family and that you will help her to do so
  - That she will attend the clinic's support group
  - That she will return for a follow-up visit in one month (or the timeframe that you feel is appropriate)
- Assist:
  - Provide her with referrals to a support group, so that she can meet others who have lost a parent
  - If you feel she is depressed or suicidal, refer to a psychiatrist or other mental health worker
  - Accompany her when she meets with family to discuss her future
  - Assist the family in coming up with the best possible plan
  - Offer to assist with any ARV or CTX refills that she might need
- Arrange:
  - Follow-up appointment, including family members as needed
  - Phone the mental health professional to make an appointment (if needed)
  - Record key points of today's discussion for her clinic record

### **Case Study 2:**

A 17-year-old woman named Taonga tested positive for HIV 6 months ago. She is caring for her 3 younger sisters with the help of her grandmother. She is so busy that she has missed a couple of appointments at the ART clinic. Her partner is the only one who knows she is HIV-positive, and he himself has not been tested. How do you proceed with Taonga today?

#### **Key point for trainers: Taonga**

- Assess:
  - Knowledge, beliefs and concerns related to HIV, particularly as she was just diagnosed 6 months ago and has missed a couple of appointments She has probably spoken to clinic staff only a couple of times thus far

- Understanding of the care plan, as she is relatively newly diagnosed she may not understand long term plans around ARVs, CTX, how often she needs to come in, etc.
- Risk factors: is Taonga practising safer sex? Is she using a reliable family planning method as well? She has at least disclosed to her partner, which is the most difficult part.
- Taonga's relationship: does it appear to be a healthy relationship that is mutually caring? Is the relationship ever violent? Is she ever fearful of him? Listen carefully when she talks about her partner; is the relationship a source of happiness? Does she blame him for her HIV infection?
- Adherence to her medications, if she has missed clinic appointments there is a good chance that she has also missed doses of medication, that is, if she is on any medications.
- Coping skills: how is she doing as the primary caregiver of her 3 siblings, in what ways does she enjoy this role and in what ways does she begrudge it?
- She has only disclosed to one person, why is this? Does she need the additional support that disclosure to her grandmother or a friend might bring?
- Her clinical status
- Acknowledge Taonga's commitment to her family and her maturity in putting her sisters' needs before her own; praise her efforts to take care of herself; talk about how she can best balance her own needs with that of siblings
- Advise:
  - Provide her with accurate information about HIV. Be guided by her questions.
  - That between now and her next appointment, that she write down her questions about HIV as they come to her, and that she bring her list with her the next time.
  - Her of the long-term care plan, when she can expect to go on ARVs and CTX and how often she needs to return to the clinic. Stress the importance of not missing appointments.
  - About safer sex and family planning. Ask that she brings her partner in for counselling and, if he consents, HIV testing.
  - About practical ways to positively cope with the situation (for example, ask her about what she enjoys doing, how she has coped with challenges in the past). If she is not coping well with her home responsibilities, try working with her on a solution. Offer to disclose to her grandmother with Taonga present or on her behalf.
- Agree:
  - That she will return to the clinic for her next appointment; when she comes she will have her list of questions
  - That she will ensure she takes her medicine (if she has been prescribed any medications)
  - That she will practise safer sex with her boyfriend

- That she will bring her boyfriend with her when she comes in the next time
- That she will think about how she can cope better with caring for her 3 siblings but still ensure she has time to take care of herself
- Assist:
  - With disclosure to a friend or her grandmother, if this is what she would like (role play or offering to disclose on her behalf)
  - By referring her to the family planning clinic
  - By referring her to the adolescent support group
  - Provide her with condoms if you have them
- Arrange:
  - Couples counselling appointment, if she agrees
  - Follow-up appointment
  - Record key points of today's discussion for her clinic record

### **Case Study 3:**

A 10 year-old boy named Mumba, who comes to clinic today with his mother, looks like he is “feeling down.” You sense that “he wants to talk to someone” but seems very quiet and won't make eye contact with anyone. How do you proceed with Mumba?

#### **Key point for trainers: Mumba**

- Assess:
  - His clinical status to ensure that Mumba's mood isn't due to disease progression.
  - Ask Mumba how he is doing. If he's hesitant to speak, start by saying, “you seem down today, can you tell me why?,” and/or use communication approaches which are appropriate for a younger adolescents, such as reading or playing a game together to build an initial relationship with the client.
  - If Mumba is still not talking, ask his caregiver to allow you to speak with Mumba in private. Mumba's quiet mood may be due to something serious (physical health, serious problem in the home) or maybe he's quiet because his mother disciplined him for talking back to her or getting a poor grade in school.
  - If there are serious social issues at home, encourage Mumba to discuss as a way of sharing his burdens. Help him and his family to develop a plan to deal constructively with the issues.
  - Assess his understanding of his care at this point in time as well as adherence to medication (we'll assume he been on medications for a while, as he was probably perinatally infected)
  - Although you want to acknowledge and praise Mumba's efforts, if his issue is with his caregiver, you also need to be supportive of the caregiver's role.
- Advise:
  - Counsel on the importance of adhering to his ART regimen as well

- as his clinic visit schedule
- Support Mumba on the issues he is dealing with; advise if needed
- Encourage him to attend the clinic's pre-teen support group
- Agree:
  - On a plan to address the key issues as identified by Mumba
  - That he will attend the clinic's support group
  - That he will return for a follow-up visit
- Assist:
  - Provide him with referrals to a support group and any other referrals, if needed
  - Offer to counsel Mumba and his caregiver together, if that might help in coming to an agreement on a way forward
  - Offer to assist with any ARV or CTX refills that he might need
- Arrange:
  - Follow-up appointment
  - Phone a mental health professional to make an appointment (if needed)
  - Record key points of today's discussion for her clinic record



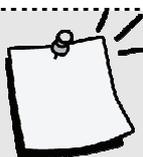
### **Trainer Instructions**

Slides 27-30

#### **Step 8:**

Explain that many adolescents who are known or suspected to be HIV-infected often face stigma and discrimination from teachers, children, neighbours, family members, and even healthcare workers. Identifying and addressing stigma and discrimination is important, because they profoundly affect the psychosocial well-being of clients and caregivers.

Ask participants to brainstorm the definitions of stigma and discrimination. Record responses on flip chart and fill in content as needed.



### **Make These Points**

- Stigma means having a negative attitude toward people we think are not “normal” or “right”. Discrimination is the unfair treatment of someone because he or she is different.
- Stigma and discrimination take many forms: stigma towards others, self-stigma, and secondary stigma.
- Stigma and discrimination have long-term effects on clients and caregivers. Most importantly, they can prevent access to HIV prevention, care and treatment services.

## Overview of Stigma and Discrimination

**Table 5.2: Definitions of Stigma and Discrimination**

**Stigma:** Having a negative attitude toward people that we think are not “normal” or “right.” For example, stigma can mean not valuing PLHIV or people associated with PLHIV.

**To stigmatise someone:** Seeing them as inferior (less than, below) because of something about them. A lot of times people stigmatise others because they do not have the right information or knowledge. People also stigmatise others because they are afraid.

**Discrimination:** Treating someone unfairly or worse than others because they are different (for example, because someone thinks a person has HIV). Discrimination is an action that is typically fuelled by stigma.

### There are different kinds of stigma:

- **Stigma towards others:** Having a negative attitude about others because they are different or assumed to be different (for example, the girl with HIV felt isolated at school because of the stigmatising attitudes of her peers).
- **Self-stigma:** Taking on — or feeling affected by — the cruel and hurtful views of others. Often, self-stigma can lead to isolating oneself from family and community (for example, Helen is HIV-positive and is afraid to “give the disease” to her family, so she keeps to herself and eats her meals alone.).
- **Secondary stigma:** People, such as community healthcare workers, doctors and nurses at the HIV clinic, children of parents with HIV, caregivers and family members, are stigmatised by their association with PLHIV (for example, when May’s male acquaintance found out that she was seeing an HIV doctor, he ended their budding relationship).

### There are different forms of discrimination:

- Facing violence at home or in the community
- Being kicked out of school
- Not being able to attend school
- Not being able to get a job
- Being isolated or shunned from the family or community
- Not having access to quality healthcare or other services
- Being rejected from a church, mosque or temple
- Police harassment
- Verbal discrimination: gossiping, taunting, scolding
- Physical discrimination: insisting the person uses separate eating utensils or occupies separate living space

**Stigma and discrimination deter access to HIV prevention, care, and treatment services for many people. Stigma and discrimination can prevent people — including adolescents — living with HIV and their families from living a healthy and productive life.**



### **Trainer Instructions**

Slides 31-35

**Step 9:** Next, ask participants to brainstorm about some examples of stigma and discrimination they have observed against ALHIV or people living with HIV in the clinic or in the community. Record responses on a flipchart.

Facilitate a discussion by asking the following questions:

- *What can you suggest to adolescents to help them deal with stigma and discrimination?*
- *What can you do in the clinic to reduce stigma and discrimination against young people?*

**Step 10:** (optional) Ask the adolescent co-trainer (if she or he is willing and comfortable) to talk about an occasion when she or he experienced or observed stigma and/or discrimination in the clinic or community.



### **Make These Points**

- Stigma and discrimination increase an adolescent's resistance to receiving help and contribute to their existing discomfort and fear around accessing healthcare services.
- Stigma and discrimination can especially impact and act as a profound barrier to care for most-at-risk adolescents, who we will discuss in Session 5.3.
- As healthcare workers, we are all responsible for challenging stigma and discrimination. We can all play a role in educating others and advocating new attitudes and practice.

## **Effects of Stigma and Discrimination**

### **Stigma and discrimination can also:**

- Keep ALHIV from accessing care, treatment, counselling and community support services, because they want to hide their status.
- Make adolescents feel isolated and as if they do not fit in with peers.
- Make it difficult for ALHIV to succeed in school.

- Motivate ALHIV to stop taking their ARVs, so that they can feel “normal”.
- Keep people from testing for HIV.
- Motivate people with HIV to have sex without disclosing their HIV status.
- Make it hard for people to tell their partner(s) their test result.
- Make it hard for people to discuss safer sex with partners.
- Cause a great deal of anxiety, stress or depression.
- Make it hard for parents to disclose their own HIV status to their children; make it difficult for caregivers to tell HIV-infected children their HIV diagnosis.
- Discourage pregnant women from taking ARVs or accessing other PMTCT services.
- Prevent people from caring for PLHIV in their family, in the community and in healthcare settings.
- Can impact some adolescents more than others. For example, orphans who are HIV-positive may encounter hostility from their extended families and community, and may be rejected, denied access to schooling and healthcare, and left to fend for themselves.

## **Strategies to Deal with Stigma and Discrimination**

### **Individual strategies for dealing with stigma:**

- Stand up for yourself and talk back.
- Educate others.
- Be strong and prove yourself.
- Talk to people whom you feel comfortable with.
- Ignore people who stigmatise you.
- Join a support group.
- Try to explain the facts.
- Avoid people who you know will stigmatise you.
- Taking and adhering to medicines and ART reduces stigma around HIV, helps normalise HIV and allows the community to see HIV as a chronic disease. People who openly taking ART can reduce stigma around the disease.

### **Strategies for dealing with stigma within healthcare settings:**

- Make sure young people and young people living with HIV, such as Peer Educators, are part of the care team. This includes making sure they attend regular staff meetings, trainings and other events.
- Make sure young people are given opportunities to evaluate clinical services and that feedback is formally reviewed by managers and healthcare workers.
- Ensure there are linkages with community based youth groups and support groups for ALHIV; refer adolescents to these groups.

- Talk openly with other healthcare workers about your own attitudes, feelings, fears, and behaviours. Support each other to address fears and avoid burnout.
- When you witness discrimination in the healthcare setting, challenge it. For example, if you see a colleague being rude to a client with HIV, after the client leaves, talk to this colleague on a one-to-one basis. Tell her what you saw and how the situation could have been handled differently.
- Report to the clinic manager discrimination in the clinic setting that is directed towards people living with HIV or their families.
- Listen to clients when they talk about their feelings and concerns about stigma and discrimination, and report these back to other healthcare workers.
- Work with other members of the multidisciplinary team to identify where stigma and discrimination exist in the clinic and work together to make changes.



### **Trainer Instructions**

**Step 11:** Allow 5 minutes for questions and answers on this session.

## Session 5.3

# Providing Psychosocial Support Services for the Most-At-Risk Adolescent



**Total Session Time:** 60 minutes (1 hour)



### Trainer Instructions

Slide 37

- Step 1:** Begin by reviewing the session objective, listed below.
- Step 2:** Ask participants if they have any questions before moving on.

### Session Objective

**After completing this session, participants will be able to:**

- Provide psychosocial support services, including referrals, to most-at-risk ALHIV.



### Trainer Instructions

Slides 38-42

- Step 3:** Explain that some ALHIV are more vulnerable than others and have different, more complex psychosocial needs. Ask the following questions to guide discussion:
- *Thinking back to Module 2, what are some factors that make adolescents especially vulnerable to the impacts of HIV?*
  - *What are some of the physical, social, and psychological problems that ALHIV, who are especially vulnerable or most-at-risk, experience in your community?*
  - *Are any of these problems or psychosocial needs different for young men and women? How?*



### Make These Points

- Most-at-risk adolescents can have greater, more complex psychosocial needs. They are generally more vulnerable to risky sexual behaviours, have less access to education and healthcare, and face greater degrees of neglect and abandonment.

- Most-at-risk ALHIV are among society's most marginalised groups. They generally have few connections with social institutions, such as schools and organised religion, where many support services are provided.
- Most-at-risk adolescents may be more fearful and reluctant to disclose personal information to a healthcare worker. As with all adolescents, it is important to always use good communication skills and adopt adolescent-friendly approaches, in order to engage and support most-at-risk ALHIV.

## Overview of Most-at-Risk ALHIV<sup>1,2</sup>

Most-at-risk ALHIV include young people who are HIV positive and particularly vulnerable or at risk, such as young people who are homeless, homosexual, trans-gendered, disabled, imprisoned, caregivers, orphans, migrants, refugees, gang members, sex workers, and injecting drug users. Most-at-risk adolescents may live in especially difficult circumstances and typically experience enormous challenges in meeting their own basic needs for food, shelter, and safety.

Young people who most need support often have the most difficulty accessing services and adopting behaviours that protect them from

HIV. The behaviours that put them at risk (for example, exchanging sex for money, food, or shelter) are usually heavily stigmatised and take place secretly, often illegally.

“Most-at-risk” refers to behaviours, while “vulnerability” refers to the circumstances and conditions that make most-at-risk behaviours more likely.

Existing policies and legislation, lack of political support, and other structural issues often prevent most-at-risk adolescents from receiving the services that they need. Such factors contribute to marginalising these young people further, which then contributes to undermining their confidence in health and social services, and their willingness to make contact with service providers.

Worldwide, all adolescents are vulnerable and at-risk because:

- Young people's behaviour is less fixed than adults' behaviour. Drug use and particular sexual practices are sometimes experimental and might or might not continue.
- Young people are less likely than older adults to identify themselves as drug users or sex workers. This makes them harder to reach with programmes and less responsive to communication addressed to groups with specific identities.
- Young people are more easily exploited and abused.
- Young people have less experience coping with marginalisation and illegality.
- Young people might be less willing to seek out services, and service providers might be less willing to provide services to them because of

concerns about the legality of behaviours in some settings and informed consent.

- Young people are often less oriented toward long-term planning and thus might not think through the consequences of the risks that are related to the choices they make.
- Many adolescents are living without parental guidance and support.
- There is a lack of accessible health, social, educational, and legal resources for adolescents.
- Adolescents might live in societies or communities where laws, cultural practice, or social values force young people to behave in ways that place them at risk, for example, homophobia, female genital cutting, or norms that encourage adolescent girls to have sex with older men.

Most-at-risk ALHIV may require more psychosocial support because they are experiencing extreme challenges such as:

- Displacement.
- Severe social exclusion/isolation/stigma/discrimination (young women can face additional gender discrimination, which can affect access to healthcare, food allocation, access to education, and other social and economic opportunities).
- Exploitation.
- Substance abuse.
- Having parents, siblings or peers who abuse drugs or alcohol.
- Migration (internal and external).
- Trafficking.
- Not being connected to the usual community supports such as schools, faith-based organisations, or the formal workplace.
- Poverty due to the poor economic climate or because they are part of a child-headed household.
- Physical or sexual abuse and violence. Adolescents working on the street are subject to the everyday risk of being sexually abused and experiencing violence at the hands of both adults (caregivers, police and others) and their peers. Many of them do not have access to health services. Their major concern is survival, and they are often involved in theft or prostitution because they do not have other means of earning money.
- Young men who have sex with other males may be unsure about their sexuality and not have anyone to talk to because of the stigma surrounding homosexuality and bisexuality.
- Chronic mental health issues, psychiatric disorders, and learning disorders: research indicates that most-at-risk adolescents are at greater risk for anxiety, depression, and anger. Studies have concluded that vulnerable youth, such as those orphaned by AIDS, experience high levels of psychological distress and material support alone is not sufficient.
- Disabilities.
- Stressful past: many situations and events that pushed these youth into vulnerable circumstances in the first place (like parental illness and

death, lack of substitute parental care, physical and sexual abuse and adverse external circumstances) may have a lasting impact on their well being.



### **Trainer Instructions**

Slides 43-49

#### **Step 4:**

Continue by explaining that as healthcare workers, we have the responsibility to engage most-at-risk adolescents by ensuring that the clinic offers youth-friendly services.

- *As healthcare workers, how do you identify or recognise ALHIV that are living in vulnerable circumstances?*
- *What do you do to respond to the needs of most-at-risk adolescents in your clinic?*
- *What support services are available for most-at-risk adolescents in your clinic and in the community?*
- *What challenges or barriers do you experience identifying and attending to the needs of most-at-risk adolescents in your clinic?*



### **Make These Points**

- As healthcare workers, we need to reach out to those adolescents who are most vulnerable to the impact of HIV and who have the least access to health services.
- Healthcare workers can engage most-at-risk youth by ensuring a youth friendly, welcoming, confidential, and nonjudgemental attitude.
- A major challenge for healthcare workers is to keep most-at-risk ALHIV connected to care and treatment as well as meeting their needs for emotional support and counselling.
- Other approaches with most-at-risk youth include: using easy-to-understand language, encouraging enrolment in peer support groups, having an effective referral system in place to provide linkages to community support, and ensuring that young people participate meaningfully in the planning and decision making around clinic services.
- Healthcare workers can help ALHIV move out of high-risk situations, help prevent their situation from deteriorating, and help prevent ALHIV from moving to the category of most-at-risk.

## **Providing Psychosocial Services to Most-at-Risk ALHIV<sup>3,4</sup>**

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### **Identifying most-at-risk ALHIV**

**Identification of most-at-risk ALHIV is a complicated task.** A review of services for most-at-risk young people found that outreach by peers has often proven to be the best way of making contact with them.

ALHIV who are especially vulnerable may show distress through feelings of suffering or difficult behaviours. This difference is sometimes referred to as having internal symptoms or external symptoms. To recognise or better identify ALHIV who are especially vulnerable, healthcare workers should pay attention to the following behaviours when conducting a clinical assessment or exam:

Internal symptoms and behaviours include:

- Unresolved grief
- Anxiety and/or depression (see Module 6 for more information about Mental Health and ALHIV)
- Poor self esteem and feelings of unworthiness
- Poor self care, including not adhering to HIV care and treatment
- Lack of self-protective behaviours, for example staying involved with sexual partners who are violent
- Inability to accept help and support from other people
- Feelings of being numb and detached
- Loss of motivation about working toward goals for the future

External symptoms and behaviours include

- Easily frustrated or impatient with simple and reasonable rules
- History of truancy
- History of stealing
- Destroys property
- Initiates physical fights
- Justifies hurting others
- Exhibits signs of substance abuse (or suspected by friends and family)
- History of physical aggression to people or animals
- Threatens caregivers or family with self-harming, self destructive behaviour, or violence
- History of running away from home
- Refuses to acknowledge impact of behaviour on others
- Exhibits emotional or mental cruelty to others

Of course an adolescent can demonstrate both types of symptoms and behaviours, but the ones that are external tend to be more troublesome to others and therefore more likely to be recognised. In addition, hazardous alcohol and substance use, suicide risk, difficulties trusting adults and mental illnesses can be seen with both types of symptoms and behaviours.

## **Providing support to most-at-risk ALHIV**

All young people should receive information, psychosocial support, and HIV care and treatment services, including services related to sexual and reproductive health. For especially vulnerable young people or those ALHIV who are most-at-risk, programmes should include all of the activities and services provided to the general population of adolescents, plus actions that are designed to reduce the risk and related harm of their behaviours, as well as support to stop these behaviours.

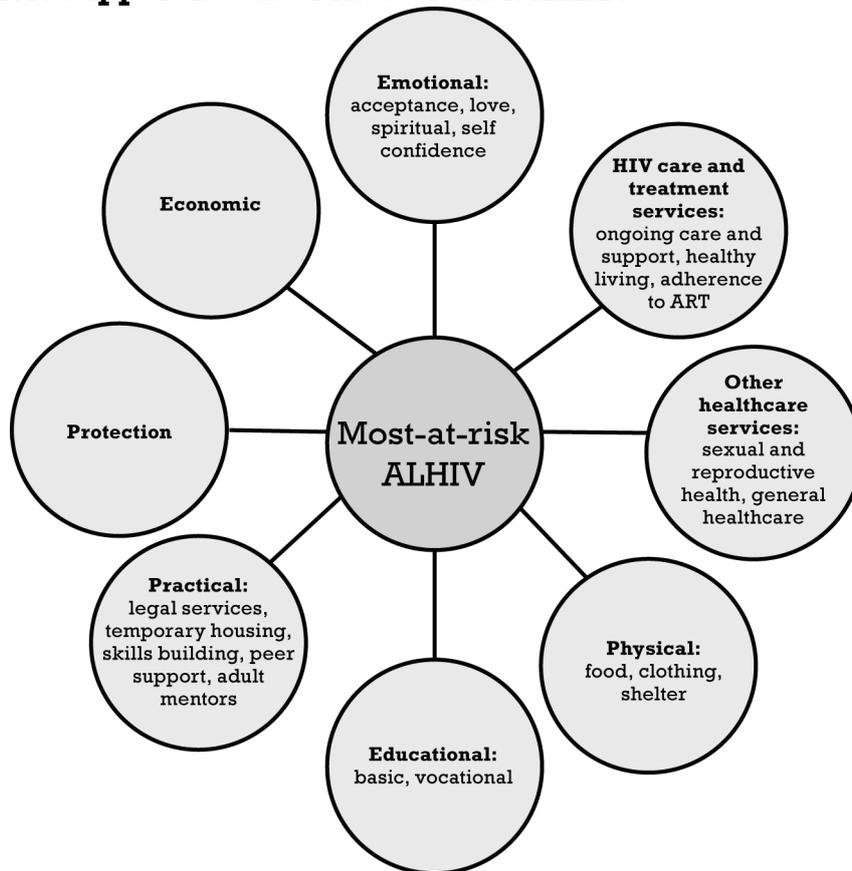
Key psychosocial interventions with most-at-risk ALHIV include:

- Promoting behaviour change, such as the use of condoms and reduction in number of sexual partners.
- Promoting positive behaviours associated with HIV treatment, care and support, including adherence to ART and the diagnosis and treatment of sexually transmitted infections (STIs).
- Teaching risk-reduction skills to help them negotiate condom use, develop strategies for refusing unprotected sex and avoiding clients who are alcohol/drug affected and potentially violent.
- Encouraging enrolment in a peer support group; peer support is particularly useful in bringing information to most-at-risk adolescents, who do not have access to teachers, parents, or other supportive adult mentors.
- Asking about and encouraging supportive relationships in the adolescent's life (for example, extended family members, friends, supportive neighbours).
- Exploring the possibility of reconnecting the adolescent to immediate or extended family, if this is appropriate and feasible. This can be done by clinic staff or by referral to an organisation that does such work in the community.
- Remember that all adolescents have wishes to be helped and supported by adults as well as peers, although they often do not want to show this. Adolescents refusing adult help are often waiting to see if the adults will persist and thereby prove that they care and are trustworthy.
- Developing an effective referral system with follow up and linkages to social, legal, NGO, faith-based organisations, and community-based youth services, to help most-at-risk adolescents meet their basic needs. Helpful services can include: assistance with school fees and supplies; child care for younger siblings so that adolescents can attend school; adult mentors that help adolescents with such skills as vocational development, income generating activities, parenting skills, and household maintenance; and general emotional support.
- Using adolescent-friendly approaches: art, drama, music, and dance often involve youth more easily than more traditional educational materials. Youth friendly services are particularly important for most-at-risk adolescents, because they are the most difficult to engage in care, are the most fearful of healthcare workers, and have the least access to services.

- Ensuring that young people participate in the planning and decision making around clinic services. Involving young people as advocates and as peers to make contact with, and provide outreach to, vulnerable and most-at-risk young people.

The support needs of most-at-risk adolescents is presented schematically in Figure 7.1.

**Figure 7.1: Support needs of most-at-risk ALHIV**



### Transactional sex: putting young women at risk

Transactional sex can include occasional exchange of sex for money, goods, or services. Significant age disparities are common in transactional sex. Among other factors, concern about HIV has prompted older men to seek younger sexual partners under the assumption that they are less likely to be infected. Young women are often willing to participate in these partnerships for emotional reasons; perceived educational, work, or marriage opportunities; monetary and material gifts; or basic survival.

These young women may fail to realise their vulnerability to abuse, exploitation, reproductive health risks and HIV. Transactional sex puts girls and young women at risk of HIV because of low condom use and the likelihood that the male partner is older and HIV positive.



#### Trainer Instructions

Slides 50-53

**Step 5:** Lead participants through Exercise 2, which provides an opportunity to discuss how to meet the psychosocial needs of most-at-risk adolescents, using case studies.

#### Exercise 2: Psychosocial Support to the Most-at-Risk Adolescents: Large group discussion using case studies

<b>Purpose</b>	<ul style="list-style-type: none"> <li>To discuss how healthcare workers can meet the psychosocial needs of most-at-risk-adolescents</li> </ul>
<b>Duration</b>	30 minutes
<b>Advance Preparation</b>	<ul style="list-style-type: none"> <li>None for this exercise</li> </ul>
<b>Introduction</b>	Most-at-risk adolescents have more complex psychosocial needs and require greater attention and advocacy from healthcare workers. In this exercise, we will bring together information, which has been discussed in the previous session and practise identifying and addressing psychosocial needs for this population.
<b>Activities</b>	<p><b>Large Group Discussion</b></p> <ol style="list-style-type: none"> <li>1. Ask participants to review the case studies in their Participant Manuals, refer to “Appendix 5A: Psychosocial Assessment Tool” and revisit the 5 “A’s” in Table 3.6 (Module 3).</li> <li>2. Write “<b>Assess</b>”, “<b>Advise</b>”, “<b>Agree</b>”, “<b>Assist</b>”, and “<b>Arrange</b>” on flip chart paper posted at the front of the room.</li> <li>3. For each of the case studies, below, identify the</li> </ol>

	<p>important issues in relation to each of the 5 “A’s”. Record these issues on a flipchart under each “A.”</p> <p>4. (optional) Encourage participation from the adolescent co-trainer, who can act as the client in the role play. Ask the following questions to encourage his or her input and participation:</p> <ul style="list-style-type: none"> <li>• <i>What did the healthcare worker do to build trust and rapport with you?</i></li> <li>• <i>Was there anything else the healthcare worker could have suggested or done to address your psychosocial needs?</i></li> </ul>
<b>Debriefing</b>	<ul style="list-style-type: none"> <li>• Summarise the session by noting that health services for young people need to be adapted to ensure that the needs of the most marginalised adolescents are met.</li> <li>• It is important that healthcare adopt a simple, standard protocol for assessing the psychosocial needs of most-at-risk adolescents.</li> <li>• Probably the most important role of the counselling is to give adolescents a place where they know they will be heard. Key psychosocial interventions can include: advice around behavioural change, referral to support services, including peer support groups, services to help adolescents reconcile with supportive adults in their life, and ensuring a non-judgemental attitude.</li> </ul>

**Exercise 2: Psychosocial Support to the Most-at-Risk Adolescents:  
Large group discussion using case studies**

**Case Study 1:**

Patrick a 16-year-old homeless youth, with no recent family contact and a history of alcohol abuse. Patrick was diagnosed with HIV 6 months ago. During his visit with you, Patrick appears dishevelled and in need of a wash. He says he has difficulty taking his medications; he forgets his schedule, often loses medication. He says that he has not told anyone that he is living with HIV. How would you proceed with Patrick?

**Key point for trainers: Patrick**

- Assess (using a psychosocial assessment guide):
  - Under the assumption that Patrick’s appearance and non-adherence to his ART regimen are due to the fact that he is homeless and/or alcoholic, you ultimately want to get to the underlying reason for his homelessness/alcoholism. Could it be mental health issues, HIV-related brain impairment, substance abuse, or a dysfunctional family life? Use the psychosocial assessment (such as that in Appendix 5A) to guide this assessment. It may take more than one session with Patrick to gain his trust to the point where he will share openly with you.
  - Support network: it appears he does not have a support network,

but enquire further, maybe he has a friend, sibling or other relative with whom he may be willing to reconnect.

- Clinical status to ensure that the cause of his mental illness is not due to disease progression.
- Although he has not disclosed to anyone, disclosure might be a topic that needs to wait for a later session, right now the focus should be his homelessness, as so much will fall into place once his life is stabilised
- His dreams for his future.
- Acknowledge Patrick's difficult situation; praise his efforts to cope.
- Advise:
  - Based on your findings around the underlying reasons for homelessness.
  - As an interim measure, counsel him to find ways to adhere to his ART regimen.
  - On his use of alcohol.
  - Him to set goals for himself, based on his future dreams — maybe returning to school or finding a job.
- Agree:
  - That he will make steps to address underlying reasons for homelessness (maybe that would be to see a counsellor, seek substance abuse counselling, try to reach out to his family, etc).
  - That he will attend the support group at least twice.
  - That he will try the agreed plan to better remember to take his ARVs.
  - That he will return for a follow-up visit in one week (or the timeframe that you feel is appropriate).
- Assist:
  - Him with referrals to a support group.
  - Him with referrals to a counsellor, psychiatrist or other mental health worker.
  - Offer to accompany him when he meets with family or to role play the discussion with a family member.
  - Offer to assist with any ARV or CTX refills that he might need.
- Arrange:
  - Appointments based on assessment.
  - To phone the mental health professional to make an appointment (if needed).
  - That key points of today's discussion are recorded in her clinic record.

### **Case Study 2:**

Kasonde is a 15-year-old girl who acquired HIV perinatally. Her mother died when she was 3 years old. She doesn't know her father and, for the last year, has been living with her 28-year-old boyfriend. She comes to the clinic today because she thinks she is pregnant. How would you proceed

with Kasonde?

### **Key point for trainers: Kasonde**

- **Assess (using a psychosocial assessment guide):**
  - Her clinical status, including pregnancy testing
  - Assuming she is pregnant, assess her feelings around this pregnancy (To what extent is she happy to be pregnant? To what extent does she feel like it is going to ruin her life?).
  - Disclosure: has Kasonde disclosed to her partner?
  - Risk factors: are Kasonde and her partner practising safer sex (it obviously isn't "safe" all the time; ask about condom use and number of partners)?
  - Kasonde's relationship: does it appear to be a healthy relationship that is mutually caring? Is the relationship ever violent? Is she ever fearful of him? Listen carefully when she talks about her partner; is the relationship a source of happiness? Does she blame him for her HIV infection?
  - Why, at the age of 15, is she living with a partner (rather than with her family)?
  - Adherence to her medications, assuming she is pregnant and having unsafe sex, she now has multiple reasons (in addition to her own health) for adhering to her medications.
  - Her future plans (will she stay in school? Will she drop out and expect her partner to support her?)
  - If she needs additional support
  - Acknowledge Kasonde's situation; praise her efforts to take care of herself
- **Advise:**
  - Assuming the pregnancy test is positive, provide counselling and refer her to ANC where she will also have access to PMTCT services. Advise her of the benefits of PMTCT services; provide her with accurate information about mother-to-child transmission of HIV. Be guided by her questions.
  - Her of the importance of disclosure to her partner, if she hasn't disclosed to him already. Offer to disclose to her partner with Kasonde present or on her behalf.
  - About safer sex. Ask that she brings her partner in for counselling and, if he consents, HIV testing.
  - About her relationship, based on your assessment. For example, if it is violent, discuss this, support her to recognise that she deserves to be in a mutually supportive relationship.
  - About any underlying reasons for her decision to live with a boyfriend at such a young age (unstable home life, lack of self-esteem, searching for love, poverty, etc).
  - Her of the continued importance to adhere to her ART regimen, every single day.
  - Her to stay in school (assuming she is still in school).

- On the availability of other support services (counselling, young mothers support group, etc).
- Agree:
  - That she will attend ANC and join the PMTCT programme and that she will continue to come to her routine ART clinic appointments
  - That she will come up with a plan to disclose to her partner (if she hasn't done so already).
  - That she will practise safer sex with her partner.
  - That she will bring her boyfriend with her when she comes in the next time.
  - That, for the moment, she will stay in school.
  - That she will ensure she takes her ARV regimen and any other medications that have been prescribed (CTX).
- Assist:
  - With disclosure to her partner, if she hasn't done so already (role play or offer to disclose on her behalf).
  - By referring her to supportive services (for example, young mothers support group or counsellor).
  - By finding ways to boost her self-esteem (school, hobby, volunteer work, support her to recognise her own strengths, etc).
  - By referring her to the ANC clinic and telling her what to expect once she arrives.
  - By offering to meet with concerned family members to enlist their support.
  - By providing her with condoms if you have them.
- Arrange:
  - Couples and/or family counselling appointments, if she agrees
  - Follow-up appointment.
  - Appointment at ANC clinic, peer support group, other referrals based on assessment.
  - To record key points of today's discussion for her clinic record.

### **Case Study 3:**

Sonkwe is 16 years old. He comes to the clinic and starts shouting and banging on your desk. He claims someone from this clinic told his mother that he is HIV-positive and she has kicked him out of the house. Sonkwe says that he has “nowhere to go” and that he has been living in a street camp since the fight with his family. How would you proceed with Sonkwe?

#### **Key point for trainers: Sonkwe**

- Assess (using a psychosocial assessment guide):
  - Sonkwe is obviously angry, listen to him, find out why he is angry (Why does he think someone from the clinic breached his confidentiality? What happened during the argument with his mother? What has happened since he left the house? Is he still angry about his HIV diagnosis?) Chances are, once he is able to

express his anger, he will calm down and agree to deal with his situation rationally. Spend the bulk of the counselling session on anger diffusion; ensure him that you are taking the accusation of a breach of confidentiality seriously. If you do not take his complaint seriously you will be unable to win his trust, and he will be unlikely to return for follow-up appointments in the near future. Cover the remaining points, if you have time and if he is willing to talk further (see Module 4 for a review of communication challenges with adolescents).

- Risk factors: is Sonkwe practising safer sex? What other risks are in his life (drug/alcohol abuse, poor nutrition)? How is he supporting himself on the streets (is he stealing? Exchanging sex for money?)?
- Support network: does Sonkwe have anyone who knows he is HIV infected with whom he can get support? Does he, for example, have a partner?
- His relationship with his mother.
- His adherence to medications.
- His future plans (will he stay in school? Is he thinking about future job prospects?).
- His clinical status to find out if there are any underlying physical reasons to explain his outburst (progression in HIV disease, etc).
- Acknowledge Sonkwe's situation; praise his efforts to take care of himself.
- Advise:
  - Based on the assessment.
  - Him that you will investigate the breach in confidentiality — if someone in the clinic is to blame, that person will be disciplined. Breaches in confidentiality can lead to dismissal.
  - Him to practise safer sex, discuss how he can negotiate condom use given his sexual practises and situation (for example, if he has a regular female partner, then he would negotiate differently than if he is exchanging sex for money and most of his customers are men). Do not automatically assume that Sonkwe is heterosexual! Ensure you have created an environment in which he will feel comfortable disclosing his sexuality!
  - Him to identify one person with whom he can seek support.
  - Him to consider how to amend the relationship with his mother.
  - Him to adhere to his medications: work out a plan based on his current situation (people who are homeless often have difficulty adhering because of the instability of their personal situations).
  - Him to continue coming to the clinic.
  - Based on his plans for his future.
  - Him to stay in school (if he is still in school or can re-enrol).
  - On the availability of other support services (counselling, support groups, etc).
- Agree:
  - On a plan based on the assessment.

- That you will investigate his accusation of a breach of confidentiality.
- That he will practise safer sex.
- That he will consider who he can disclose to that will give him support.
- That he will think about taking the first step to amend the relationship with his mother and that you would be willing to help him with this, including meeting with him and his mother together.
- That he will ensure he takes his ARV regimen and any other medications that have been prescribed (CTX).
- That he will continue to come to the clinic and join a support group, or attend other services as recommended by the assessment.
- That he will stay in school.
- Assist:
  - By investigating a credible accusation of breach in confidentiality
  - By giving him condoms (if available).
  - By supporting disclosure to a friend (offer to role play).
  - By offering to discuss the situation with his mother. His mother's extreme reaction may be due to misconceptions about HIV that the healthcare worker can identify and correct.
  - By referring him to support services based on the assessment (support group, counsellor, housing services, etc).
  - By finding ways to boost his self-esteem (school, hobby, volunteer work, support him to recognise his own strengths, etc).
- Arrange:
  - Follow-up appointment.
  - Appointment at the organisation to which he has been referred.
  - To record key points of today's discussion for her clinic record.



### **Trainer Instructions**

**Step 6:** Allow 5 minutes for questions and answers on this session.

## Session 5.4 Peer Support in Psychosocial Services for Adolescents



**Total Session Time:** 35 minutes



### Trainer Instructions

Slide 55

- Step 1:** Begin by reviewing the session objective, listed below.
- Step 2:** Ask participants if they have any questions before moving on.

### Session Objective

**After completing this session, participants will be able to:**

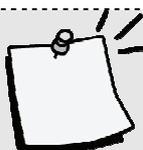
- Understand the importance of peer support in meeting adolescents' psychosocial support needs.



### Trainer Instructions

Slides 56-59

- Step 3:** Explain that young people face stronger peer pressure, are constantly seeking approval and involvement of other youth in their lives, and look to their peers for guidance — especially if they consider peers as their only family. Because adolescents are greatly influenced by the beliefs and actions of others their age, peer education and peer support can help meet adolescents' psychosocial support needs, especially for those who are most-at-risk. Ask the following questions to guide discussion and record responses on a flip chart:
- *How can peer support help address the psychosocial needs of ALHIV?*
  - *Why is this particularly important for most-at-risk adolescents?*



### Make These Points

- Adolescents may trust the support and practical advice from peers more than they do that from adults.
- Peer support is particularly effective for adolescents with limited family

connections, who turn to their peers for information and connection.

- Peer outreach is the most effective way of making contact and engaging most-at-risk adolescents in HIV care and treatment services. Peer support can help clients understand their illness and the need to return to the clinic even if they are not on ART.

## **Importance of Peer Support for ALHIV**

Adolescents generally depend on peers for information, approval, and connection. This is particularly true for most-at-risk adolescents — such as, street children — who do not have guidance from parents, teachers and other adults. In addition to the other psychosocial support strategies described in this Module, peer support can help ALHIV to counter stigma and discrimination, to cope with fear and hopelessness after diagnosis, to improve adherence to care and treatment services, and to deal with issues such as disclosure to partners, friends and family.

**The engagement of ALHIV as Peer Educators can play an important role in improving adherence and service quality.**

### **Peer Educators can help improve services for ALHIV**

Full participation of Peer Educators in the health facility and outreach services can expand the clinic's ability to provide quality care by allowing the already overburdened healthcare workers to concentrate on more technical tasks. Depending on the context and programme, Peer Educators can play a number of important roles in HIV service delivery, including but not limited to:

- Providing individual counselling and long term support (adherence preparation, adherence follow up, disclosure, positive living, positive prevention, etc.) at ART clinics.
- Providing psychosocial support to clients and family members enrolled in HIV care and treatment.
- Leading health talks and group education sessions with ALHIV, caregivers, treatment supporters and others.
- Assisting clients with disclosure.
- Linking young pregnant women living with HIV to ANC and PMTCT services.
- Assisting clients with referrals from place to place within or between health facilities.
- Providing referrals and linkages to community-based services and support.
- Tracing clients who miss appointments or who have been lost to follow up.
- Serving as a communication link between clients and healthcare workers.
- Participating in outreach and education activities related to HIV in the community.

- Assisting with the design and delivery of peer support groups for ALHIV and their caregiver.

Peer support for ALHIV can help address adolescents' psychosocial support needs by:

- Helping youth feel they are accepted and valuable members of the group and reduce their sense of isolation.
- Helping clients solve their own problems.
- Providing emotional support.
- Promoting learning, sharing, and skill building around disclosure, adherence, and dealing with stigma and discrimination.
- Maintaining a youth's motivation and commitment to HIV care and treatment, since peer support can be stronger than adult support or personal desire alone.
- Effectively engaging most-at-risk adolescents, who tend to lack positive support networks.



### Trainer Instructions

Slides 60-63

#### Step 4:

Lead a discussion to get a sense of participants' experiences with peer support groups. First, ask participants to raise their hand if they have facilitated a support group meeting. Use these questions to guide the group discussion and fill in, as needed, from the content below:

- *Why do you think peer support groups would be helpful for ALHIV?*
- *What topics and activities do you think could be incorporated into a peer support group for ALHIV? For younger adolescents?*
- *What can you do to start or improve a support group in your area?*

Encourage participants to review "Appendix 5B: Starting/Planning a Peer Support Group", "Appendix 5C: Facilitating a Peer Support Group", and "Appendix 5D: Ideas for Peer Support Group Activities".

#### Step 5:

(optional) Ask the adolescent co-trainer to talk about his or her experiences with peer support groups, if applicable.



### Make These Points

- Healthcare workers have a role in initiating and facilitating peer support groups and linking ALHIV with existing support groups.

- While there are many different types of support groups, their purpose is the same: to reduce isolation and provide psychosocial and emotional support to their members.
- Members of peer support groups help each other to improve and better manage their situation, share challenges and discuss solutions. Members support each other to implement decisions taken to meet their psychological, social, physical, and medical needs.

## **Peer Support Groups for ALHIV**

Peer support groups are groups of people who come together because they share a common situation. In peer support groups, members help each other to improve and better manage their situation, share challenges and discuss solutions. Members support each other to implement decisions made to meet their psychological, social, physical and medical needs.

- Very often people living with HIV feel isolated and alone. Meeting other people living with HIV can reduce isolation and provide encouragement to live more fully and positively.
- Support groups can help increase the uptake of healthcare services, such as HIV testing, PMTCT and HIV care and treatment. Support groups can help members to better understand clinical services, give them support to seek and adhere to care, and provide support for integrating family members into care.
- Support groups also offer ways to link members to healthcare services and community-based services. For example, healthcare workers or leaders of community-based organisations can talk about the range of services their organisations offer during support group meetings. Support group members typically share with each other their experiences with local service providers and swap advice on how to navigate each programme (for example, ideal time to arrive to reduce wait time, which documents to bring to the initial appointment, etc).
- Depending on the specific programme, Peer Educators may play an important role in starting support groups, facilitating support group meetings and/or helping others organise them and recruit members for them. Peer Educators in these roles will benefit from support and mentoring.

### **A sampling of the range of support groups:**

- **Adolescent support groups:** ALHIV may want to form their own support groups to discuss some of the special challenges that they face. These groups may involve recreational activities (sports, crafts, drama, etc.), as well as time for discussion. It is best if they are led by an adolescent enrolled in care and treatment, such as a Peer Educator. Peer Educators in this role will benefit from support and mentoring to help them problem solve difficulties that may arise (for example dealing with withdrawn or disruptive members).

- **Playgroups for younger adolescents:** Children living with HIV and their caregivers may benefit from groups where children of similar ages can play together and where caregivers have a chance to share and talk. These groups often involve child-friendly activities, such as games, drawing, art and music.
- **Young mothers support groups:** Young mothers living with HIV and those with HIV-exposed or HIV-infected children may want to have their own support group. Young mothers support groups can provide needed psychosocial and emotional support and help mothers understand and access key HIV and PMTCT services. These groups can address concerns specific to mothers, such as safer infant feeding, care of HIV-exposed babies, and the importance of adherence to PMTCT and ART services.
- **Adolescent grief group:** The loss of a loved one is an extremely painful experience for anyone, including adolescents. Loss can be particularly difficult if it is the loss of a parent, children expect their parents to always be able to protect them from harm. One way that adolescents can cope with the loss of a loved one is to join a bereavement group.
- **Couples support groups:** Couples, including those where both people are living with HIV as well as discordant couples, may wish to form support groups. Couples can share common concerns and challenges and support one another to live positively with HIV.
- **Post-test clubs:** These groups are for anyone who has been tested for HIV. Therefore, they do not require participants to identify their status when joining. They often focus on promoting HIV information and education in the community, but they also provide a social environment for the members to meet each other and discuss any important issues, including how to stay negative, being in a discordant relationship, etc.
- **Groups for other specific populations:** Other groups of people with common characteristics may wish to form their own support groups. This could include sex workers support groups, support groups for men who have sex with men or others. In some places, there are support groups just for single people to meet other singles living with HIV. In areas with a diverse population, groups of people that have the same ethnicity or speak the same language may wish to form their own support groups.

### **Ideas for health education topics that can be incorporated into support group meetings:**

- Positive living
- Navigating the healthcare system
- Disclosure
- Coping with school
- Relationships and sexuality
- Dealing with stigma

- Adherence
- Preventing opportunistic infections
- Nutrition
- Domestic violence
- Family planning and dual protection
- Preventing new HIV infections
- Dealing with death and dying of a friend or family member



### **Trainer Instructions**

**Step 6:** Allow 5 minutes for questions and answers on this session.



### **Trainer Instructions**

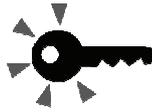
Slides 64-66

**Step 7:** Ask participants:

- *What are the key points of this module?*
- *What information from this module will you be able to use in your workplace?*

**Step 8:** Summarise the key points of the module using participant feedback and the content below.

**Step 9:** Ask if there are any questions or clarifications.



## Module 5: Key Points

- Psychosocial support addresses the ongoing emotional, social and spiritual concerns and needs of people living with HIV, their partners, their family and caretakers of children living with HIV.
- Healthcare workers play a key role in assessing clients' psychosocial needs. Healthcare workers can use a Psychosocial Assessment Tool to help assess clients' psychosocial needs and help counsel them to come up with their own solutions.
- Healthcare workers should remember the 5 "A's" when conducting a psychosocial assessment: **ASSESS** the client's needs, **ASSIST** with referrals and support, **ADVISE** the client and help him/her make an informed decision, **AGREE** on goals, and **ARRANGE** a follow-up appointment.
- Stigma means having a negative attitude toward people that we think are not "normal" or "right." For example, stigma can mean not valuing PLHIV or people associated with PLHIV. Self-stigma is when a person is affected by the cruel and hurtful views of others, which can lead to isolating oneself from family and community.
- Most-at-risk adolescents include ALHIV who are vulnerable, such as young people who are injecting drug users, homeless, sex workers, trans-gendered, disabled, imprisoned, caregivers, orphans, migrants, refugees, and gang members. Health services for young people need to be adapted to meet the needs of most-at-risk.
- Good psychosocial support can reduce the number of adolescents who are in the most-at-risk category.
- Offer to include caregivers' and/or family members' input into the assessment as needed and agreed upon by the adolescent, while simultaneously protecting the confidentiality of information.
- Healthcare workers and peers can engage and help support the psychosocial needs of ALHIV, especially those who are most-at-risk, and can help them to have better access and adherence to HIV prevention, care and treatment services.

## **Appendix 5A: Psychosocial Assessment Tool**

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### **How to Use this Tool**

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This psychosocial assessment guide was developed to support a range of providers (trained counsellors, lay counsellors, healthcare workers, and others) who work with ALHIV and their families. Conducting a psychosocial assessment with each client (and caregiver, if applicable) helps to learn more about his or her specific situation, to prioritise needs, and to give direction to ongoing counselling and psychosocial support. This includes referrals for needed community and home-based services.

A psychosocial assessment should be conducted with **each adolescent client after enrolment in HIV care and treatment services**. Healthcare workers may want to conduct another psychosocial assessment or revisit specific psychosocial issues when a client's situation changes in a significant way, such as when a client reaches a new developmental stage or starts to show signs that there are new challenges/problems. Always respect client confidentiality and conduct sessions in a space that offers visual and auditory privacy. Key information from the psychosocial assessment should be recorded on the form and the form kept in the client's file for reference during follow-up visits. A template to record follow-up counselling notes is also included.

**Basic information:** Write down the client's name and file number. Be sure to sign and date the form at the end of each session.

**Questions to ask the client/caregiver:** The questions in these sections allow the healthcare worker to discuss and assess the client's psychosocial issues and needs. It is important to allow time for the client to respond to each question. Clients should always be made to feel comfortable expressing psychosocial challenges and should never be judged or punished. Write down any important information from their responses, as this will help decide on effective next steps, important areas for follow up, and in supporting the client's psychosocial wellbeing over the long term.

**Questions, summary, and next steps:** Ensure that the client has time to ask questions and that the healthcare worker has time to summarise the session and agreed upon next steps. Record key next steps in the space provided.

**Additional notes:** Write any additional notes about the session or the client's psychosocial needs in the space provided.

**Referrals made:** Linkages and referrals to psychosocial support services are important elements of HIV care and treatment programmes and the ongoing support of adolescent clients and their families. Each clinic should have an up-to-date list of community support services (such as Peer Educators, adherence supporters, ALHIV associations, food support,

education and job training programmes, legal support, etc.) and formal two-way referral systems to these organisations and services. Clients with severe psychosocial and psychological issues (such as depression, use of drugs and alcohol, feeling suicidal) will require careful follow up and immediate referrals to ongoing professional counselling and other services. Record any referrals made to the client in the space provided. At the next session, follow up to determine if the client accessed these services.

**Date of next counselling session/clinic appointment:** Schedule a follow-up counselling appointment with the client and record this date, as well as any clinic appointments in the space provided.

**REMEMBER:**

- Do not talk down to an adolescent.
- Allow an adolescent to speak for himself/herself. Respect their opinions.
- Be patient! Allow the adolescent to express her views and describe her experiences.

# ALHIV Psychosocial Assessment Guide and Recording Form

Client Name: \_\_\_\_\_ Client File#: \_\_\_\_\_

<b>Coping, Support System, and Disclosure</b>	
1. Smile, introduce yourself and give a short explanation of your role. Explain that this discussion will be confidential.	
2. Can you tell me how things have been going since you learned your HIV-status? How are you coping? <b>Explore and discuss client's coping strategies</b>	
3. Let's talk about your living situation. Who are you living with? How long have you lived with them? How well do you get along you're your caregiver? Who else is in your household? Which of them have HIV infection? How are they doing? <b>Assess living situation</b>	
4. <i>If not living with parents, ask:</i> Where are your parents? When did this happen? How did this affect your living situation? What other caregivers have you lived with?	
5. Who do you feel close to? Who can you go to for emotional support? <b>Counsel on importance of social support</b>	
6. Tell me what you do. Do you, for example, go to school or work outside the home?	
7. How often in the last week have you used cigarettes, alcohol, or other drugs? <b>Assess for harmful coping strategies, such as drug/alcohol use, and provide counselling and referrals</b>	
8. To whom have you disclosed your HIV-status? What was their reaction? Do you want to disclose to anyone else to get the support you need? If so, how will you do this? What support do you need? <b>Counsel on full and partial disclosure</b>	Yes No
9. Do you belong to a community/religious organisation or support group that gives you the support you need? Would you be willing to join a support group, to meet other ALHIV?	Yes No Name/location of organisation or group:
10. We have all felt rejected or isolated at some point in our lives. Have you experienced negative attitudes or treatment because of your HIV-status or other reasons? Has anyone caused you harm in the past; for example, hurt you physically or unwanted sexual encounters? <b>Counsel and discuss available support</b>	Yes No Details:

<b>services</b>	
<p>11. How is your mood now? Do you feel sad or depressed? What changes have you noticed in your mood? What about in your eating habits? In your sleeping pattern? Do you have less energy than usual? Have you lost interest or pleasure in things you usually enjoy? <b>Assess risk of depression and need for referral to a mental health expert, etc.</b></p>	
<p>12. Do you have financial support from your family or partner, a regular source of income, or do you receive help, such as social grants, food parcels, or anything else? <b>Counsel and refer to social worker and community-level support</b></p>	<p>Yes No Sources of income/support:  Receiving social grant? Yes No</p>
<p>13. Other than coming to this clinic, where else do you go for health services (for example, other clinics, traditional healers, etc.)?</p>	
<p>14. Many adolescents have sex with their partners. Are you having sex? If so, what family planning method did you use the last time you had sex? (If client is sexually active and did not use condoms the last time, ask) When was the last time you used a condom? <b>Screen for sexual risk taking and counsel on safer sex and family planning</b></p>	
<p>15. How do you/will you remember to take your medications every day? How will you remember when to come back to the clinic? Who can help you? <b>Counsel on adherence to care and medicines and briefly discuss:</b></p> <ul style="list-style-type: none"> <li>• <b>WHO</b> will give or manage medicines?</li> <li>• <b>WHAT</b> will you do to remember?</li> <li>• <b>WHEN</b> will you take them?</li> <li>• <b>WHERE</b> will you store your medicines?</li> <li>• <b>HOW</b> will you remember to take your medicines (review use of reminders, like calendars, pill boxes, etc)</li> </ul>	

**Questions, Summary, and Next Steps**

<p>16. What other questions or concerns do you want to discuss today?</p>	
<p>17. Summarise the session and review immediate plans and next steps, including the next clinic visit date</p>	<p>Note next steps here and in the space below:</p>

Notes:

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**Referrals made:**

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**Date of next counselling session/clinic appointment:** \_\_\_\_\_

**Healthcare worker signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

Adapted from: ICAP. 2010. Improving retention, adherence, and psychosocial support within PMTCT services: A Toolkit for Health Workers. New York, NY: Columbia University/ICAP.

## **Appendix 5B: Starting/Planning a Peer Support Group**

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### **Key steps to think about when starting/planning a support group**

**First, find out what HIV-related support groups already exist in the area. Then, try to understand what support groups are needed:**

- Work in partnership with clients, counsellors, social workers, and/or Peer Educators to determine what types of support groups are needed.
- Ask adolescents who attend the clinic when they could come to a meeting, where they would like the meeting to be held and what they would like to talk about (for example, adherence strategies, stigma, disclosure).

### **Decide WHO the support group is for:**

- Who will be invited to attend? Generally, it is best to have different support groups for younger and older adolescents.
- What is the ideal number and type of participants? It is recommended that support groups not have more than 10–15 people in the same meeting so that everyone can participate.

### **Define the overall goals of the support group:**

- What is the purpose of the support group?
- What will members gain from the support group?
- Is the support group meant to go on indefinitely, or will it cover a certain number of topics and then come to an end?

### **Recruit support group members:**

- How will you let people know about the support group?
- Will members of the multidisciplinary team refer people to the support group? How will it be advertised?

### **Decide on the location of the support group meetings:**

- Can it be held at the health facility? Is this convenient for adolescents or should it be located in the community?
- If support group meetings are held at a health facility, will members be able to get HIV services before/after the meeting?

### **Decide how often the group will meet:**

- What time and how often will the groups be held? Do most participants go to school during the day or do they have household chores at certain times of the day? Is 1 hour enough or is 2 hours better?
- Will the group meet once each month? More often? Less often?

### **Develop the meeting agenda**

- Who will run the support group?

- Who will be invited to speak? What is the topic?
- Will there be guest speakers?

**Think about venue, food, and other logistics:**

- Is there privacy at the meeting space?
- Are there enough places for people to sit?
- Can the room be arranged so participants are in a semi-circle (instead of in rows)?
- Will you arrange for tea or snacks for the meeting? Who will get them? How will they be paid for? Who will keep attendance and other records of the support group?

**Suggested agenda items for support group meetings**

- Registration/sign-in
- Refreshments (tea, coffee, snacks, etc.)
- Welcome/opening (song, prayer, dance)
- Introductions
- Overview of the agenda
- Reminder about confidentiality and other ground rules
- Main group learning activity (game, health talk, etc)
- Questions and answer session (make use of an anonymous question box)
- Plan for the next meeting
- Closing (song, prayer, dance, etc.)

**Most support group meetings last between 1–2 hours.**

**Make sure to suggest and plan new learning opportunities and fun activities for support group members:**

- Keep everyone busy and having fun! Use games and participatory activities (refer to suggestions in “Appendix 5D: Ideas for Peer Support Group Activities”)
- Consider including a health talk as a part of each support group meeting. The health talk can be focused on a different topic area at each of the meetings. Health talks should be kept short and simple (about 15–20 minutes) so that support group members have time to discuss their feelings, questions and concerns.
- Plan an activity or ongoing project for each group meeting that relates to the overall theme of the group.
- Get feedback from support group members on topics they would like to discuss during the meetings and incorporate these into the agenda. This can be done through an anonymous questions box.

## **Appendix 5C: Facilitating a Peer Support Group**

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### **Set up the room so that everyone can participate:**

- Encourage participants to sit in a semi-circle to make it more comfortable to talk and less like a classroom.
- The person leading the meeting should be part of the semi-circle.
- If possible, provide tea or a light snack for members, facilitators and invited guests.

### **Remind participants about confidentiality:**

- Support group members will only feel open to discuss their experiences and feelings if they know others will ensure the discussion is kept confidential.
- It is always a good idea to remind support group members at the start of each meeting that what is said during the meeting is not repeated in the community.

### **Ask participants to establish ground rules:**

- During the first group meeting, ask the participants to brainstorm the group's ground rules. Ground rules might include any of the following: we respect others' opinions, we will not interrupt, we will allow everyone a chance to speak, we will not tolerate homophobic comments, etc.

### **Offer participants ongoing support and referrals:**

- Encourage participants to speak with you or another facilitator in private afterwards if they have concerns they do not want to share with the group.
- Know what support and services are available in the community and at nearby health facilities so you can provide referrals.
- If the meeting takes place at a health facility, try to time it so members can seek services before or after the meeting.
- Seek input from multidisciplinary team members and other experts on topics beyond your area of expertise.
- Create a plan for situations where support group members need assistance right away (for example, if they are mentally distressed, suicidal, violent or the victim of violence).

### **Keep records of the meeting:**

- Always keep an attendance record. Remember, this information is confidential.
- Ask someone to take simple notes during the meeting. Note what topics were discussed, key concerns of members, and any next steps. Also note the date, time and location of the next meeting.

- All meeting records must be stored in a locked cabinet to ensure confidentiality.

**Be a good facilitator or co-facilitator:**

- Partner with a Peer Educator, social worker or counsellor as a co-facilitator. Decide what role the co-facilitator will play during the meeting.
- Create a safe and welcoming environment for support group members. Support groups should not feel like health education sessions or lectures. Instead, members should feel that this is “their” meeting.
- Be sure to plan the meeting agenda ahead of time and practise what you are going to say.
- Lead an introductory activity (have people introduce themselves or say something about their family) so participants feel more comfortable with one another.
- Review the agenda with support group members and ask if there are questions. Always ask for suggestions for the next meeting agenda.
- Stick to the agenda and keep time!
- Use the 7 listening and learning skills when leading a support group meeting:

**7 Listening and learning skills**

- Skill 1: Use helpful non-verbal communication.
- Skill 2: Actively listen and show interest in the client.
- Skill 3: Ask open-ended questions.
- Skill 4: Reflect back what the client is saying.
- Skill 5: Empathize — show that you understand how the client feels.
- Skill 6: Avoid words that sound judging.
- Skill 7: Help the client set goals and summarise each session.

## Appendix 5D: Ideas for Peer Support Group Activities

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### Charades

Players try to act out terms or concepts without speaking.

- **Materials:** Watch or timing device, pieces of paper (cut a sheet of A4 paper into eights; papers can be blank or already containing health terms), two baskets, hats or other containers for the paper, scorekeeping method.
- **Play:** Form teams. Divide the paper between the two teams. If the paper is blank, allow the teams to privately consult and fill in the blanks with terms, phrases or concepts related to material they are learning. Choose a neutral timekeeper/scorekeeper, or have the teams take turns. Review the gestures and hand signals and invent any others as needed.

To play, teams take turns having a player choose a piece of paper from another team's basket. Without speaking, the player has 3 minutes to use gestures and actions to help his or her team members guess what is written on the piece of paper.

Normally the game continues until every player has had a chance to "act out" a phrase. Scoring may be based on one point for every paper correctly guessed. Another scoring option is based on the total time that each team needed for all of the rounds; with this system, the team with the lowest score wins the game.

### Sculpturing

Participants put themselves in certain poses using their whole body, including gestures and facial expression, to communicate an image of an issue or relationship. The 'sculpture' is then discussed.

- **Play:** Ask participants to get in pairs then ask the pairs to make a sculpture showing how people treat orphans. Ask them to decide on roles. One person is the orphan, the other is a community member. Then ask some pairs to show their sculptures in the centre of the circle. After each demonstration, ask:
  - *What do you think this person is saying?*
  - *How do you think these people are feeling?*

Ask the people in the sculpture:

- *What are you thinking?*
- *Why are you doing that?*

- *How are you feeling?*

## **Journaling**

Ask participants to create “All About Me” journals using magazines, markers, and other materials, which can be used for decorating the journal. Ask participants to think of the special characteristics (hobbies, traits, etc) that make up their identity. Also include future goals and dreams. A counsellor or Peer Educator at the clinic may want to write back/respond to client’s journal entries in writing.

## **Question box**

Create a box at the health facility for anonymous questions. Ask clients to drop in questions any time. These questions can then be picked out of the box at random during one portion of the support group meeting and discussed by everyone.

## **Songs**

Ask participants to work in small groups to create a song about a health topic, positive living or reducing stigma.

## **Plays/drama**

Ask participants to work in small groups to create a play about, for example, combating stigma in schools or the community.

## **Arts and crafts games**

These games help adolescents to think about themes in their lives in new ways — and can be quite useful for appealing to younger adolescents who enjoy doing activities that are hands-on, participatory and creative. One technique for slowing down youth who rush through art projects is to tell them that within the time frame, the LAST artists to finish are the winners.

**Example:** Create a painting or drawing of a scene where participants were discriminated against; ask participants to discuss their feelings about this.

## References and Resources

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<sup>1</sup> WHO/UNICEF. 2008. *Global Consultation on Strengthening the Health Sector Response to Care, Support, Treatment and Prevention for Young People Living with HIV*. Geneva, Switzerland: WHO/UNICEF.

<sup>2</sup> Working Group, U.S. Agency for International Development, the Joint United Nations Programme on HIV/AIDS (UNAIDS) Inter-Agency Task Team on HIV and Young People, and FHI. 2010. *Young People Most at Risk of HIV: A Meeting Report and Discussion Paper from the Interagency Youth*, Research Triangle Park, NC: FHI, 2010.

<sup>3</sup> Working Group, U.S. Agency for International Development, the Joint United Nations Programme on HIV/AIDS (UNAIDS) Inter-Agency Task Team on HIV and Young People, and FHI. 2010. *Young People Most at Risk of HIV: A Meeting Report and Discussion Paper from the Interagency Youth*, Research Triangle Park, NC: FHI, 2010.

<sup>4</sup> Working Group, U.S. Agency for International Development, the Joint United Nations Programme on HIV/AIDS (UNAIDS) Inter-Agency Task Team on HIV and Young People, and FHI. 2010. *Young People Most at Risk of HIV: A Meeting Report and Discussion Paper from the Interagency Youth*, Research Triangle Park, NC: FHI, 2010.



# Module 6                      Adolescents, HIV, and Mental Health



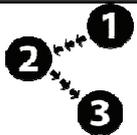
**Total Module Time:**            175 minutes (2 hours, 55 minutes)

## Learning Objectives

**After completing this module, participants will be able to:**

- Identify their own beliefs and attitudes about mental health and ALHIV.
- Discuss why ALHIV need access to mental health services.
- Describe common mental health issues faced by adolescents.
- Distinguish between mental health problems and mental illness.
- Discuss ways to screen and treat some common mental health issues and neuropsychiatric disorders affecting ALHIV.

## Methodologies



- Interactive trainer presentation
- Large group discussion
- Small group work
- Case studies
- Role play

## Materials Needed



- Slide set for Module 6
- Flip chart and markers
- Tape or Bostik
- Participants should have their participant manuals. The participant manual contains background technical content and information for the exercises.

## References and Resources



- Colton, T., Dillow, A., Hainsworth, G., Israel, E., & Kane, M. 2006. *Community home-based care for people and communities affected by HIV/AIDS: A comprehensive training course for community health workers*. Watertown, MA: Pathfinder International.
- Frank, L. 2006. *Adolescents, HIV, and Mental Health*. AETC National Resource Center and AETC Adolescent HIV/AIDS Workgroup.
- Mellins, C.A., Brackis-Cott, E., Dolezal, C., Abrams, E.J. 2006. Psychiatric Disorders in Youth with Perinatally Acquired Human Immunodeficiency Virus Infection. *Pediatric Infectious Disease Journal*; 25(5):432–437.



### Advance Preparation



- Read through the entire module and ensure that all trainers are prepared and comfortable with the content and methodologies.
- Review the appendices in this module ahead of time and prepare to incorporate them into the discussion.

### **Session 6.1: Importance of Mental Health Services for ALHIV**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation	5 minutes
Exercise 1: Values Clarification: Large group discussion	25 minutes
Interactive trainer presentation and large group discussion	20 minutes
Questions and answers	5 minutes
Total Session Time	55 minutes

### **Session 6.2: Assessing Mental Health and Providing Basic Mental Health Support to ALHIV**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation and large group discussion	60 minutes
Exercise 2: Mental Health Assessment and Support: Role play and large group discussion	45 minutes
Questions and answers	5 minutes
Review of Key Points	10 minutes
Total Session Time	120 minutes

## Session 6.1      Importance of Mental Health Services for ALHIV



**Total Session Time:** 105 minutes (1 hour, 45 minutes)



### Trainer Instructions

Slides 1-4

**Step 1:** Begin by reviewing the Module 6 Learning Objectives and the session objectives, listed below.

**Step 2:** Ask participants if there are any questions before moving on.

### Session Objectives

**After completing this session, participants will be able to:**

- Identify their own beliefs and attitudes about mental health and ALHIV.
- Discuss why ALHIV need access to mental health services.



### Trainer Instructions

Slides 5-7

**Step 3:** Introduce the topics of ALHIV and mental health by leading participants through a values clarification exercise (Exercise 1), which will give them an opportunity to explore and discuss some of their attitudes, values, and beliefs about this subject matter.

<b>Exercise 1: Values Clarification: Large group discussion</b>	
<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To discuss attitudes, values, beliefs, and prejudices about ALHIV and mental health issues</li> </ul>
<b>Duration</b>	25 minutes
<b>Advance Preparation</b>	<ul style="list-style-type: none"> <li>• None required</li> </ul>
<b>Introduction</b>	<p>Values are influenced by our beliefs and experiences which, in turn, affect our attitudes and behaviours. Values play a key role in the decisions we make, how we spend our time and energy and how we act. The aim of this activity is to create a safe and productive learning environment that enables the participants to discuss their attitudes and values about mental health and ALHIV.</p>

<b>Activities</b>	<p><b>Large group discussion:</b></p> <ol style="list-style-type: none"> <li>1. Ask participants to review the “<b>Statements for sentence completion</b>” in their participant manuals.</li> <li>2. The trainer should read out loud to the large group each one of the “<b>Statements for sentence completion</b>”.</li> <li>3. For each statement, the trainer should ask a participant to offer a response. To encourage discussion, the trainer should then ask the rest of the participants if they had similar or different reactions.</li> </ol>
<b>Debriefing</b>	<ul style="list-style-type: none"> <li>• Debrief the activity by explaining that in many cases, our values and beliefs influence our actions, both personally and professionally. A client’s and provider’s culture and beliefs can have a profound effect on the type of mental health problems experienced, the local terms used to describe them, beliefs associated with mental illness, and the care that is provided to clients and caregivers.</li> <li>• People with mental health issues are often stigmatised, discriminated against, and excluded from social activities. Healthcare workers can combat this stigma and discrimination by: acting as role models by setting an example for community members on how to treat people with mental health problems, helping to recognise major signs/symptoms of mental health problems, and providing support and treatment to clients and caregivers experiencing mental health problems.</li> </ul>

**Exercise 1: Values Clarification: Large group discussion**

**Statements for sentence completion:**

1. Mental illness is...
2. Mental health services in this country are...
3. The way people with mental health issues are treated is....
4. Some of the traditional/cultural beliefs about mental illness in this community are...
5. ALHIV who suffer from depression and other mental health diagnoses are...
6. An adolescent with a mental health problem should...
7. Providing mental health care at our facility is...
8. When an ALHIV shows signs or symptoms of a mental health problem, the role of the healthcare worker should be...



**Trainer Instructions**

Slides 8-15

**Step 4:**

Remind participants that, in Module 5, we discussed how HIV infection affects all dimensions of a person’s life: physical, psychological, social, and spiritual. All ALHIV experience the

normal developmental challenges of adolescence, but most face additional stressors on their mental health that impact their ability to adhere to care and treatment and to live positively with HIV.

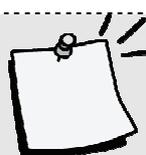
Start this section by providing definitions of some of the key terms we will be using in this module:

- Mental health
- Mental health problem
- Mental illness
- Mental disorder

**Step 5:** Ask participants the following questions to facilitate discussion and record responses on a flip chart:

- *Why is addressing the mental health needs of ALHIV important for HIV care and treatment?*
- *What are some of the stressors (related to health, family, community) experienced by ALHIV that may affect their mental health?*
- *What are some examples of times when ALHIV might need extra support with their mental health or maintaining a healthy mind?*
- *What are some of the known mental health challenges that ALHIV face, from your experience? What are some local terms for these conditions/illnesses in your country/community?*

**Step 6:** (optional) If willing and comfortable, ask the adolescent co-trainer to discuss some of the mental health challenges he or she, or someone they know, have experienced.



### **Make These Points**

- HIV is a chronic stressor that places HIV-infected persons as well as their immediate and extended families at risk for mental health problems.
- ALHIV face the same challenges as their HIV-uninfected peers. However, unlike their peers, they must deal with these challenges while living with a chronic, highly stigmatised disease.
- ALHIV face additional stressors associated with their disease, including loss and bereavement, cycles of wellness and poor health, barriers to care and community-based/social services. Additionally, poor coping skills or an inability to accept their diagnosis makes some ALHIV vulnerable to abusing alcohol and other substances.
- ALHIV are especially susceptible to many mental health challenges, such as: depression, anxiety, behavioural disorders, and

neurocognitive impairments.

- All ALHIV require routine mental health assessment and support from healthcare workers — and the entire multidisciplinary care team — to help them live positively with HIV in the long term.

## Overview of ALHIV and Mental Health<sup>1,2,3,4</sup>

Overview of mental health and mental illness

- Given the enormous amount of biological and psychological change associated with adolescence, most adolescents will experience some type of fluctuation in mood or behaviour and/or problems that affect their emotional and mental functioning.
- The task of evaluating whether an adolescent is experiencing a milder mental health problem versus a mental illness is complicated and requires extensive training.
- Although the symptoms of **mental illness** can range from mild to severe and are different depending on the type of mental illness, a young person with an untreated mental illness often is unable to cope with life's daily routines and demands.
- **Mental illness** is not a single disease but a broad classification for many disorders. Although the exact cause of most mental illnesses is not known, it is becoming clear through research that many of these conditions are caused by a combination of factors, including genetics or family history of a disorder, chemical imbalances in the brain, or stressors in the environment.
- Many **mental health disorders** of adulthood begin in childhood or adolescence.

### Definitions

- **Mental health** refers to a psychological or emotional state of an individual.
- **Mental health problem** describes the normal fluctuation in mood or behaviour that has minimal effect on life's daily routines and demands
- **Mental illness** is any disease or condition affecting the brain that significantly influences or disrupts a person's thinking, feeling, mood, ability to relate to others and daily functioning.
- **Mental disorder** is when a problem or symptom disrupts daily functioning in 1) home, 2) school, and/or 3) community. If an adolescent is able to function well in at least two of those three areas, it is unlikely that he or she has a serious mental disorder.

### Importance of mental health services

Providing mental health services to ALHIV is important because:

- Both mental health problems and mental illness are common among ALHIV.
- Mental health status influences the course of HIV disease in various ways. For example, depression can limit the energy required to keep

focused on staying healthy, and research shows that depression may accelerate progression to AIDS.

- A person's mental health significantly influences his or her adherence to HIV care and treatment. Mental health problems can prevent people from taking their medications correctly. Studies have shown that 2 of the major factors causing non-adherence are mental health problems and substance abuse. Studies in adults have found that when depression is treated, clients with HIV are more likely to adhere to their ART, experience improved CD4 cell count and lower viral load.
- People who experience mental health problems (for example, depression), are more likely to abuse drugs or alcohol and to engage in risky sexual behaviours, such as improper or no condom use.
- Our mental health and our physical health are closely related — which is why helping people deal with mental health problems can help them live positively.
- Access to mental health services has been shown to decrease HIV disease progression and death.

## **Stressors**

In addition to the normal developmental challenges of adolescence, ALHIV also have to cope with multiple HIV-related conflicts and stressors in their lives. Stressors, such as the following, can be risk factors for mental health and social problems:

- Anxiety about medical prognosis
- Anger at parents about being HIV positive (ALHIV who were perinatally infected)
- Loss and bereavement
- Loss of caregivers, particularly when caregiver is not replaced by an adequate substitute (adolescents who are heads of household and those who are homeless are at risk of mental health problems due to hardship and lack of traditional support systems)
- Anxiety over physical appearance and body image (for example, delayed development, wasting, and dermatologic conditions)
- Emotional pain related to social stigma, isolation and hopelessness, forced disclosure
- Social and emotional isolation (lesbian/gay/bisexual/transgender youth are particularly vulnerable to a range of physical and mental health problems)

## **ALHIV need extra support with their mental health:**

- When they first learn about their HIV diagnosis (symptoms of depression may be common immediately after learning HIV status).
- When feeling rejected or as if they don't fit in with their peers.
- When feeling upset, frustrated or angry about living with HIV (for example, having to take medicines every day, having to hide medicines when at school or around people that don't know their HIV status, coming to the clinic and missing out on opportunities with friends).

- After learning a family member is living with HIV.
- When preparing to disclose to friends or family members.
- When worrying about dating, having sex, or fantasizing about having children in the future.
- When starting ART or changing regimens.
- When having problems with personal relationships with friends or partners.
- When grieving the loss of a loved one.
- When facing stigma, discrimination, or violence in school, at home, or in the community.
- When experiencing any significant any physical illness.
- Upon recognising new symptoms/progression of disease (for example, major drop in CD4 cells, rise in viral load).
- When hospitalised (particularly the first hospitalisation).
- When exhibiting signs or symptoms of persistent mental illness, such as depression, anxiety, drug and alcohol abuse, or other behavioural problems.

These are all important times for healthcare workers and members of multidisciplinary care team to provide extra emotional support, but ongoing mental health support is also needed to help people live positively with HIV in the long term.

### **Common mental health problems or disorders in adolescents**

Many mental health problems emerge in late childhood and early adolescence. ALHIV are especially susceptible to many mental health challenges, such as:

- Depression (a feeling of intense sadness — including feeling helpless, hopeless, and worthless — that lasts for days to weeks).
- Anxiety (a feeling of nervousness, fear, or worry that interferes with the ability to sleep or otherwise function).
- Behavioural disorders, such as violent behaviour, aggression, and impulsivity (the tendency to do things without adequate forethought).
- Eating disorders (for example, overeating, not eating enough, dieting to the point of starvation, binge eating and then purging).
- Neurocognitive impairments (HIV-infected children and adolescents are at increased risk of developing central nervous system disease characterised by cognitive, language, motor, and behavioural impairments).
- Somatic complaints (complaints relating to the body, not the mind or spirit): Anxiety and depression affect the mind and the body and, when severe, are routinely accompanied by physical (or somatic) complaints. These may include fatigue, headaches/migraines, abdominal pain/gastrointestinal problems, back aches, difficulty in breathing/chest pain. Somatic symptoms can also occur as indicators of distress in the absence of obvious depression and anxiety. Among ALHIV it is always important to rule out medical causes.

- Suicidal ideation (thinking about suicide).
- Other behavioural problems or risky behaviours, such as drug and alcohol abuse.
- Problems resulting from side effects of ARVs or negative experiences with medications: some ARVs, like efavirenz, are known for their effect on the central nervous system, resulting in sleep disturbance and mood changes. Symptoms usually resolve but clients still need encouragement and support.
- General problems coping with HIV diagnosis, including social withdrawal, loneliness, anger, confusion, fear, and guilt.

The more common mental health problems and/or mental health disorders are discussed further in the next session.



### **Trainer Instructions**

**Step 7:** Allow 5 minutes for questions and answers on this session.

## Session 6.2 Assessing Mental Health and Providing Basic Mental Health Support for ALHIV



**Total Session Time:** 120 minutes (2 hours)



### Trainer Instructions

Slides 16-17

- Step 1:** Begin by reviewing the session objectives listed below.
- Step 2:** Ask participants if there are any questions before moving on.

### Session Objectives

**After completing this session, participants will be able to:**

- Describe common mental health issues faced by adolescents.
- Distinguish between mental health problems and mental illness.
- Discuss ways to screen and treat some common mental health issues and neuropsychiatric disorders affecting ALHIV.



### Trainer Instructions

Slides 18-22

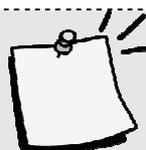
- Step 3:** Explain that most of us are not mental health experts, but we all have a role in supporting clients' mental health. This means that we should know the signs and symptoms of common mental health issues faced by ALHIV and be able to provide basic support, treatment, and referrals.

Explain that ALHIV may enter the care setting with a variety of mental health and psychosocial issues. Adolescents may also develop mental health problems as they develop and age, and these problems or issues may change over time. One of the healthcare worker's most difficult tasks is to determine the most significant problems which require more immediate attention. Other problems may need to be set aside to focus on the problems and issues that are interfering with the adolescent's quality of life and adherence to care and treatment. Encourage discussion by asking:

- *How do you think we, as healthcare workers, can screen for and recognise mental health problems in our adolescent*

*clients?*

Fill in, using the content below. Take 1 or 2 minutes to go over the content of “Table 6.1: Assessment of well being screening tool”. Remind participants about the Psychosocial Assessment form in Module 5 (“Appendix 5A: Psychosocial Assessment Tool”), and explain that this can also be used to assess and obtain an initial understanding of ALHIV’s mental health needs.



### **Make These Points**

- Healthcare workers should conduct a basic screening of mental health problems at every clinic visit, and ask caregivers about any changes in the client’s behaviour at home, with friends, and at school. Healthcare workers should also observe behaviour during clinic visits to validate findings from the screening tool.
- Factors such as poverty, low education, and unemployment are associated with higher rates of mental illness and may be seen as risk factors for the development of mental illness.
- Systematic screening of adolescents for behavioural problems, mental health problems, and serious mental health issues is critical because it leads to early detection and treatment, and the possible prevention of more serious problems.

## **Recognising Common Mental Health Problems in ALHIV**

- Symptoms of depression and anxiety are very common among adolescents. They are often transient and respond to support from friends, family and healthcare workers. The presence of a mental illness should be suspected when symptoms:
  - Are persistent, unresponsive to simple support, and/or
  - Cause severe distress or result in reduced ability to carry out ordinary activities such as self-care, maintaining social relationships and attending to schoolwork or other activities.
- Diagnosing a mental illness by interviewing an adolescent is difficult and requires years of specialised training, but all healthcare workers should be able to screen for major signs and symptoms of basic mental health problems. An example of a basic, routine mental health screening tool for use with clients or caregivers during routine check ups can be found in Table 6.1.
- It is important to assess a client’s mental health needs at every visit and to ask caregivers about the clients’ moods, general behaviour, and any changes they have observed — at home, at school, with friends, and with family members.

- It is also important to consider environmental factors, such as poverty, education, employment, and factors related to the family/ caregivers (for example, a change in caregiver, caregiver skill in raising an ALHIV) — all of which can be risk factors for the development of mental illness.

**Remember:** The way mental health problems present in clients will vary from culture to culture and person to person. They will also be different for younger and older adolescents. For example, it is common for younger children to manifest mental health issues through acting out behaviours or by complaining about stomach pain or other unexplained somatic problems. Older adolescents may demonstrate more pronounced difficulties with schoolwork, truancy, running away from home, and substance abuse. Significant mental health problems interfere with a sense of well-being and/or the ability to carry out usual activities. Use the Assessment of Well-being screening tool to determine if mental health problems are likely to be present.

**Table 6.1: Assessment of well being screening tool**

✓	<b>Topic and key questions</b>
	<b>1. General mood and energy level</b>
	<ul style="list-style-type: none"> <li>• <i>How are you feeling today?</i></li> <li>• <i>Would you say that you are feeling better or worse than the last time you were here?</i></li> </ul>
	<b>2. Eating, sleeping, and daily functioning</b>
	<ul style="list-style-type: none"> <li>• <i>How you have been sleeping?</i></li> <li>• <i>What types of foods have you been eating?</i></li> <li>• <i>Can you tell me about any changes in your eating and sleeping habits in the last month?</i></li> </ul>
	<b>3. Family and home</b>
	<ul style="list-style-type: none"> <li>• <i>Can you tell me more about any problems you are having at home? With your family?</i></li> </ul>
	<b>4. School or work</b>
	<ul style="list-style-type: none"> <li>• <i>Can you tell me more about how you are doing at school/work?</i></li> <li>• <i>During the last month, how often have you missed or skipped full days at school/work?</i></li> </ul>
	<b>5. Alcohol and drug use</b>
	<ul style="list-style-type: none"> <li>• <i>Can you tell me how often you used alcohol or recreational drugs in the last month?</i></li> <li>• <i>(Ask caregiver) Have you noticed any changes in _____ (name) behaviour at home, with friends, and/or at school?</i></li> </ul>
	<b>6. Support network and coping mechanisms</b>
	<ul style="list-style-type: none"> <li>• <i>Who supports you at home?</i></li> <li>• <i>Do you have any activities that you enjoy?</i></li> <li>• <i>How do you cope when you feel depressed or sick?</i></li> </ul>
<b>If the client/caregiver reports any problems that are interfering with their relationships, school/work performance, and/or ability to manage responsibilities at home, this may indicate a mental health</b>	

**problem that warrants further assessment (see next section).**

## **Behaviour during clinic visits**

The healthcare workers should also pay close attention to the client's behaviour during clinic visits, as this may provide important information about a person's mental health. Healthcare workers should observe the following:

- **Appearance:** How is the client's hygiene and grooming?
- **Behaviour:** Is the client behaving normally? Or, is the client behaving restless, "jumpy," or slow?
- **Attitude:** Is the client's attitude cooperative or belligerent?
- **Speech:** Is the client's speech normal? Or is the client's speech overly loud, slow, rapid, or slurred?



### **Trainer Instructions**

Slides 23-39

#### **Step 4:**

Start this discussion by asking:

- *If you have a client that, based on the mental health screening tool, appears to be exhibiting signs of a mental health issue, what do you do now? (Answer: provide further screening, which we will describe shortly.)*

Post 5 pieces of flip chart, each with one of the following labels, around the training room ("ANXIETY," "DEPRESSION," "DISRUPTIVE BEHAVIORAL DISORDERS," "NEUROCOGNITIVE DISORDERS," and "SEVERE MENTAL ILLNESS"). Ask participants the following questions to facilitate discussion and record responses on the relevant pieces of flip chart paper:

- *What have you heard about and what do you know about these terms? What are some ways you define these mental health problems?*
- *What are some major signs and symptoms of each of the problems listed?*
- *How would you screen and assess a client for each of these problems?*
- *How would you treat/manage each of these problems in an ALHIV client?*

As you fill in, using the content below, review the screening tools in "Appendix 6A: Screening and Management Tool for Anxiety", "Appendix 6B: Screening and Management Tool for Depression", "Appendix 6C: Screening and Management Tool for Suicide Risk", "Appendix 6D: Screening and Management Tool for Primary Psychotic Disorders".



### **Make These Points**

- The psychological and mental health issues faced by adolescents with HIV are complex, requiring careful and supportive assessment and intervention that take into account the adolescent's age and developmental stage, culture, family, community, and other environmental influences.
- ALHIV may be at greater risk for mental health problems, such as depression. According to WHO, up to 44% of people with HIV may suffer from depression. Anxiety is also very common in people living with HIV. Some clients will show signs and symptoms of both depression and anxiety. Anxiety and depression are common reactions to living with HIV, especially when people are not feeling well and do not get the support they need from family, friends, healthcare workers, and their community.
- Clients with disruptive behavioural disorders tend to exhibit developmentally inappropriate levels of attention, impulsivity, hyperactivity, and/or aggression towards people or animals.
- Adolescents who experienced severe immunodeficiency and illness as children are most at risk of neurocognitive disorders. Signs of neurocognitive disorders include memory loss and poor attention.
- "Severe mental illness" is a general term describing diagnoses that include schizophrenia and other conditions that can have psychotic features, in other words, clients with these conditions tend to see or hear things that are not there.

## **Common Mental Health Problems in ALHIV<sup>5,6</sup>**

The client who is exhibiting signs or symptoms of mental health problems based on the mental health screening tool (see "Table 6.1: Assessment of well being screening tool"), needs further assessment. Healthcare workers should develop and maintain the necessary skills to recognise, address, and in some cases prevent, the major mental health problems commonly associated with HIV.

The signs, symptoms, and treatment options of common disorders are summarised below. This content is based on guidelines from the American Psychiatric Association in the United States. Although these tools for screening and treatment of mental health disorders have not been tested in Zambia, they can at least provide some guidance for clinicians.

### **Anxiety**

Anxiety disorders, which can cause enormous distress and/or disability, are different from everyday, normal anxiety. Anxiety disorder:

- Is more intense (for example, panic attacks),

- Lasts longer (anxiety that may persist for months instead of going away after a stressful situation has passed), or
- Leads to phobias (irrational fears) that interfere with daily life.

In adolescents, anxiety is a common reaction to learning their HIV diagnosis.

### **Signs and symptoms of anxiety:**

- Cannot eat
- Cannot breathe or shortness of breath
- Shaking and sweating
- Heart pounding fast
- Tingling in the hands or feet
- Headaches
- Trouble sleeping
- Cannot concentrate on anything
- Feel “jumpy”, “stressed”, or restless
- Feel worried about many things
- Can present differently for younger and older adolescents, for example younger adolescents may exhibit acting out behaviours

Anxiety can also present as panic disorders and posttraumatic stress disorder. Healthcare workers should screen and assess clients for anxiety according to the guidelines in “Appendix 6A: Screening and Management Tool for Anxiety”.

### **Management and treatment for anxiety:**

- Counselling, including support groups
- Teach client relaxation techniques
- If there is no improvement, refer to a psychiatrist at the nearest hospital

## **Depression**

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Depression is the most common mood disorder seen in ALHIV.

### **Signs and symptoms of depression:**

- Feel like you just do not know what to do (depressed mood, helpless or hopeless)
- Really tired with no energy
- Cannot find good in anything
- Do not enjoy the things you used to (loss of interest or pleasure)
- Sleep too much or not enough
- Get angry for no reason
- Cannot eat or eat too much
- Do not feel like being social with friends or family
- Feelings of guilt or low self-worth

- Poor concentration.
- Desire for sex decreases
- Talk about running away
- Think about suicide
- Talk of self injury or prior episode(s)
- Prior attempts or expressions of suicide

These problems can become chronic or recurrent, and lead to impairments in the person's ability to take care of his or her everyday responsibilities. At its worst, depression can lead to suicide.

### **Risk factors for depression in an ALHIV:**

- Family history of depression or previous episode(s) of depression
- Dropping out of school or not accomplishing a significant goal
- Diagnosis of an illness, disease progression or hospitalisation
- Disclosure of a diagnosed illness to family and friends
- Low adaptive/coping ability
- Family financial difficulties, neglect/abuse, parental alcohol or substance abuse
- Difficulties in a romantic relationship
- Stress or trauma (including natural disasters)
- Having other behavioural or learning disorders
- Questioning sexual orientation
- Previous suicide attempt
- Loss of a parent or loved one, divorce of parents, or other losses

Healthcare workers should screen clients for depression:

- Upon enrolment into care,
- At routine check ups, AND
- Whenever symptoms of depression are reported

Healthcare workers can use the guidelines in "Appendix 6B: Screening and Management Tool for Depression" to screen and assess for depression.

### **Management and treatment for depression:**

- Family and individual counselling
- Medications
- Diet, exercise, and sleep modifications with family involvement to increase compliance
- Psychosocial counselling for problem resolution (see Module 5)
- Combination of counselling and medications
- Some things to consider before initiating medication: Consider possibility of substance use and ensure that standard medical assessment includes CD4 count. In clients with severe immunosuppression, depression can indicate a new OI. If client

recently began efavirenz, wait to see if symptoms spontaneously improve. If not, treat depression or consider ARV regimen change.

### **Screening for and management of suicide risk**

#### **Clients require urgent intervention if:**

- They indicate they might hurt themselves or another person or show any evidence of self-harm (for example, cut marks on the wrists/body)
- They are thinking about, threatening, or have attempted to kill themselves
- Their families cannot cope with them anymore and want to throw them out.

#### **Role of family and friends:**

- When clients are suicidal, caregivers, family, and friends are crucial sources of support who can reduce isolation and hopelessness.
- If family and friends are unwilling or unable to assist, provide organised support through community-based services.

See “Appendix 6B: Screening and Management Tool for Depression” and “Appendix 6C: Screening and Management Tool for Suicide Risk”. **Ensure clients assessed as high risk for suicide, are put under constant observation and hospitalised, if possible.**

## **Disruptive Behavioural Disorders**

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Disruptive behavioural disorders are marked by poorly regulated and socially unacceptable behaviours that interfere with the adolescent’s ability to carry out daily activities and negatively affect school performance. Symptoms are typically observed in younger adolescents.

### **Signs and symptoms of disruptive behavioural disorders**

The signs and symptoms of disruptive behavioural disorders (will vary depending on the type of disorder) include:

- Frequent defiance of the authority of parents, teachers and others
- Arguing and refusing to obey rules at home and school
- Failure to take responsibility for bad behaviour or mistakes
- Resentment and looking for revenge
- Regular temper tantrums

Older children and adolescents with disruptive behavioural disorders may exhibit the following behaviours as well:

- Aggressive behaviours that threaten or harm people or animals
- Behaviours that destroy property such as fire setting, breaking windows or graffiti
- Stealing, bullying or lying to get something

- Serious violations of rules, including school truancy and running away from home

Adolescents with attention deficit hyperactivity disorder (ADHD), which can co-occur with disruptive behavioural disorders, exhibit the following symptoms:

- Trouble paying attention and concentrating
- Difficulty organising activities
- Easily distracted
- Failure to finish most tasks
- High activity level
- Cannot sit still
- Impulsivity, acting without thinking
- Cannot wait for a turn
- Interrupt

### **Management and treatment for disruptive behavioural disorders:**

- Counselling with the client focusing on self-regulation
- Counselling with caregivers focusing on improvements in parenting skills and giving advice on how to create a structured home environment
- Medication
- Referral to any local support services

## **Neurocognitive Disorders**

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HIV in children is associated with developmental delays and cognitive impairments. Some children have normal development, some have mild impairment and others have severe impairment. Factors that affect the degree of impairment include the timing of HIV infection and the use of ART.

### **Signs and symptoms of neurocognitive disorders:**

- Delayed expressive language skills (problems expressing him or herself using spoken language)
- Slowed psychomotor speed (taking longer than normal to understand what someone else is saying and then respond)
- Memory deficits (experiencing a loss of memory)
- Poor attention (difficulty concentrating or paying attention)
- Developmental impairment (not developing as expected, developmental impairment is most common among children who experience severe immunodeficiency during the first few years of life)

### **Management and treatment for neurocognitive disorders:**

- Provide client and family tailored supportive counselling that meets the unique strengths, disabilities and needs of the adolescent

- Ensure that the adolescent is on an adequate ARV regimen to prevent or slow further progression of neurocognitive impairment
- Encourage caregivers to follow this general principle: reward effort, not results
- Link client and family to community based resources for children and adolescents with intellectual and developmental disabilities
- Look for areas of strength that can be developed to promote social and occupational skills
- Provide extra guidance to manage sexual impulses
- Provide the caregivers of older, stronger adolescents who are severely impaired with assistance and support to manage behavioural disturbances

## **Severe Mental Illness**

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Severe mental illness usually refers to schizophrenia, schizoaffective disorder, and other mental illnesses that can have psychotic features (in other words, loss of contact with reality). Psychotic illnesses are assumed to be primarily the result of neurotransmitter imbalances in the brain; however, psychotic disorders can also result from reactions to outside stressors or medications. In talking with clients, healthcare workers may discover psychosis exhibited by clients' bizarre ideas or delusions, or by their disorganised thinking and language.

### **Signs and symptoms of serious mental illness:**

- Bizarre delusions
- Auditory and visual hallucinations (client reports hearing or seeing things)
- Paranoia
- Agitation
- Suspiciousness
- Hostility
- Exaggerated sense of self

Healthcare workers can use the guidelines in “Appendix 6D: Screening and Management Tool for Primary Psychotic Disorders” to screen and assess for psychotic disorders in clients.

## Assessment of serious mental illness:

First rule out delirium, a serious *medical* (i.e., not psychological) condition that can also present with delusions, hallucinations (to see or perceive something that is not there) and agitation. Many serious medical conditions can cause delirium, which is characterised by rapid onset and changes in consciousness, confusion and inattention.

Head trauma can cause delirium, as can alcohol and other drugs intoxication or withdrawal. Always check for fever — an agitated adolescent who is febrile should always be presumed to be medically ill.

### Delirium

A rapid change in mental state associated with confusion and varying degrees of alertness (for example agitated one minute and drowsy the next) suggests the serious medical condition known as delirium.

**Adolescents suspected of delirium should be referred for urgent medical evaluation and treatment.**

## Management and treatment of serious mental illness:

- If delirium is *not* suspected, refer to a psychiatrist or mental health nurse for assessment and treatment (generally using prescribed antipsychotic medications)
- Clients with severe mental health disorders should not be discriminated against when ARV treatment is considered. Stabilisation of psychiatric symptoms and directly observed treatment by a caregiver or treatment supporter will likely improve adherence.



### Trainer Instructions

Slides 40-46

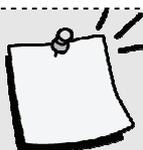
**Step 5:** Now that you have discussed with participants some of the major mental health issues seen in ALHIV, let's talk about the challenges and barriers to addressing them and what we CAN do in our setting to provide clients and caregivers with quality mental health services.

**Step 6:** Ask following questions to facilitate discussion and record key points on a flip chart:

- *What are some of the challenges or barriers to the provision of mental health services that exist in your setting?*
- *What are some things healthcare workers can do to address the mental health needs of ALHIV?*
- *What other services exist in your health facility, in nearby health facilities, and/or in your community to meet the mental health needs of ALHIV and their caregivers (for example, counselling, medication, mental health specialist, peer support groups, etc.)?*

- *What can healthcare workers do to support caregivers?*

Debrief by emphasizing that despite the many challenges to providing mental health services to ALHIV, there are things that healthcare workers can do to support clients and caregivers and to help them cope better and manage their problems more effectively.



### **Make These Points**

- Although there are barriers to providing mental health services in many settings (for example, insufficient resources, few treatment options, little data on ALHIV and mental health prevalence in sub-Saharan Africa), there are many concrete things healthcare workers can do to support clients and caregivers.
- Healthcare workers can help clients and caregivers stay mentally healthy by offering counselling and emotional support, practical suggestions about how to positively cope with life, and referring them to support groups, spiritual counsellors and other groups.
- Healthcare workers should recognise family and friends of clients as crucial sources of support for mental health problems.
- Prescription antidepressant medications are generally well-tolerated and safe for people living with HIV. When antidepressants are prescribed, monitor for drug-drug interaction and side effects.
- An important part of helping adolescents cope with mental health issues is to encourage caregivers to strengthen their relationship with the young person. This may involve talking more with the adolescent, allowing him or her to ask questions, encouraging them to talk about their feelings, and doing routine things or playing/spending time with the adolescent.

## **Providing Mental Health Support to Clients and Caregivers<sup>7,8</sup>**

### **Challenges**

Barriers and challenges to providing mental health services include the following:

- Insufficient number of mental health specialists to provide effective training and supervision of primary care workers
- Limited information on prevalence of mental health disorders in African countries
- Lack of validated and context-appropriate screening tools
- Few treatment options (for example, therapy, medication)

- Little data are available on the treatment of psychiatric disorders in ALHIV
- Social stigma of people living with persistent mental illness
- Little is known about the links between depression and other specific behavioural disorders in this population

### **Important components of mental health services for ALHIV**

The treatment for mental health problems in ALHIV is generally similar to the treatment approaches among non-infected clients. Healthcare workers providing mental health services for ALHIV should:

- Use a solution-focused counselling approach aimed at: enhancing problem-solving, brainstorming together on ways of coping including lifestyle changes, identifying choices and evaluating the value and consequences of choices.
- Include the family. If the client gives permission, ensure the inclusion of the family when providing mental health services. The advantages of family-focused services include the following: they give families a chance to discuss issues together, learn new things about each other, explore problems and then work on solutions together — ensuring a wider commitment for plans that come out of the counselling session. Family counselling can provide the building blocks for a more functional and communicative household, enhancing the wellness of the entire family.
- Encourage peer contact and support. Identify other ALHIV in the community who have adjusted to their life and are willing to talk about it. Arrange for them to meet the client and his or her family so that they can give support and inspiration.
- Refer the client to support groups for ALHIV, so he or she can meet other ALHIV who are living healthy, positive lives.
- Ensure that the basic needs (for example, food, shelter, clothing, etc.) of the ALHIV are met.
- Identify other community resources and support groups and link the client and family with them. These could be groups to help with finances, spiritual counselling, childcare, transport, or other needs.
- Provide referrals to mental health providers (for example, mental health specialists, psychologists and/or psychiatrists, if available).
- Discourage use of recreational drugs and alcohol because they can make mental health problems worse.
- Prescribe medications, when appropriate. But if not prescribed by a doctor, discourage the use of antidepressant medicines because they can have serious side effects. Even if prescribed, the caregiver must supervise their use. It can take a few weeks before antidepressants begin to improve depression, although the side effects appear right away. To be safe and effective, antidepressants need to be used consistently and in the exact doses that are prescribed.
- Be managed by a doctor AND a mental health professional — for example, a psychiatrist, psychologist, or social worker — who is in

close communication with the physician or nurse providing the HIV treatment.

- Respect and listen to clients' beliefs on the origin and healing of mental health problems. Beliefs concerning the treatment of mental health conditions vary among members of different cultural groups. Some clients will reject conventional Western methods of treating mental health disorders. Others, particularly those from communities where there is a strong sense of spirituality, may consult spiritual leaders for help. Yet other clients and caregivers will feel comfortable with interventions grounded in their own cultural traditions and practices.

### **Treating mental health problems with medication**

- Prescription antidepressant medications are generally well-tolerated and safe for people living with HIV. But like all medications, they can have side effects and require careful monitoring.
- Healthcare workers should learn about antidepressants and their interactions with HIV-related medications.
- It is important to be aware that the use of antidepressants in adolescents is sometimes associated with an increased risk of suicide.
- Any behavioural changes in a client require further assessment for possible medical problems, including drug-drug interactions.
- If medication is prescribed to a client for a mental health problem, it should, whenever possible, be combined with counselling.
- An important consideration for patients who are mentally ill is adherence to both HIV and any other medication regimens. Healthcare workers should assess a client's adherence to ALL prescribed medications at every visit.

### **Healthcare workers can support adolescent clients experiencing mental health problems by:**

- Reminding them that feelings of depression and anxiety are common, but should be managed as much as possible: *“Recognising the problem is the first step in dealing with it, therefore please ask for help if you have symptoms such as crying, loss of appetite, excessive anxiety, or feel panicked.”*
- Helping them set goals around living positively, like eating well, getting good medical care, and practising safer sex.
- Reminding them that sometimes caregivers may also be tired and discouraged. This is not necessarily directed at the client personally, but is a result of the situation.

### **Encourage caregivers**

An important part of helping adolescents cope with mental health issues is to encourage caregivers to strengthen their relationship with the adolescent. Healthcare workers can suggest that the caregivers:

- Spend time with and listen to the adolescent.
- Let the adolescent know that their painful feelings are common. Encourage them to talk and express feelings and thoughts. Listen actively.
- Communicate unconditional love and acceptance by using appropriate nonverbal gestures and verbal communication. This will give them an opportunity to understand and help them to overcome their negative feelings.
- Help the adolescent plan daily or weekly activities. This encourages them to be active and retain control of their life.
- Involve the adolescent in family activities as much as possible.
- Relax. It is important for both the adolescent and the family to learn to relax both physically and mentally.
- Get enough rest and eat well.
- Get professional help from a counsellor.
- Be aware that when emotional distress is persistent and interferes with daily activities, a mental illness may be present, and evaluation by a doctor or mental health provider is needed.
- Talk to someone; family members may also be depressed and need help.
- Get help from a support organisation in the community.
- Continue their regular religious or spiritual practices.



### **Trainer Instructions**

Slides 47-56

#### **Step 7:**

Lead participants through Exercise 2, which gives participants an opportunity to discuss how they would manage adolescent clients experiencing mental health problems in their setting.

<b>Exercise 2: Mental Health Assessment and Support: Role play and large group discussion</b>	
<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To discuss mental health assessment and provision of support to ALHIV and their caregivers</li> </ul>
<b>Duration</b>	45 minutes
<b>Advance Preparation</b>	<ul style="list-style-type: none"> <li>• None required</li> </ul>
<b>Introduction</b>	Explain that a client's general mental health should be considered at every visit. Routine screening for mental health problems should be a routine part of care. Those who are considered high-risk should then be assessed further and referred for treatment.
<b>Activities</b>	<p><b>Large Group Discussion of Case Studies</b></p> <ol style="list-style-type: none"> <li>1. Ask participants to review the 1<sup>st</sup> case study in their Participant Manuals.</li> <li>2. Invite two participants to role play the 1<sup>st</sup> case study.</li> </ol>

	<p>One will play the role of the “client” (which, for the first case study, is Mary) and the second the “healthcare worker”. The actors should take seats in the front of the room.</p> <p>3. In considering how this case study should be handled, participants should refer to “Table 6.1: Assessment of well being screening tool”, and then to either “Appendix 6A: Screening and Management Tool for Anxiety”, “Appendix 6B: Screening and Management Tool for Depression”, “Appendix 6C: Screening and Management Tool for Suicide Risk”, or Appendix 6D: Screening and Management Tool for Primary Psychotic Disorders”.</p> <p>4. The trainer should read the role play and then ask the large group following questions to facilitate discussion:</p> <ul style="list-style-type: none"> <li>• <i>What are the main mental health concerns for this client?</i></li> <li>• <i>What tools should the “healthcare worker” use to screen this client?</i></li> </ul> <p>The “healthcare worker” and “client” should role play the screening process using the tools suggested by the large group. The large group should follow using the copy of the screening tool in their Participant Manuals. At the end of the screening process (i.e. completion of the screening tool in Table 6.1) the trainer should ask the large group:</p> <ul style="list-style-type: none"> <li>• <i>What should the “healthcare worker” do next?</i></li> </ul> <p>Based on the large group’s response, the “healthcare worker” should go onto the next assessment tool, either “Appendix 6A: Screening and Management Tool for Anxiety”, or “Appendix 6B: Screening and Management Tool for Depression” and “Appendix 6C: Screening and Management Tool for Suicide Risk”, or “Appendix 6D: Screening and Management Tool for Primary Psychotic Disorders”. When that assessment is complete, the trainer may ask the actors to return to their seats and then turn to the large group to discuss interventions for this client by asking:</p> <ul style="list-style-type: none"> <li>• <i>What interventions would you recommend for this client?</i></li> <li>• <i>How would you manage this situation in your clinic? What specific actions would you, the healthcare worker, take? What services should be provided by the multidisciplinary care team?</i></li> <li>• <i>What other community-based resources should be provided to the client and caregiver?</i></li> </ul> <p>5. The trainer should repeat the same process for the next 4 case studies, inviting different participants to role play</p>
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	<p>the “healthcare worker” and “client”.</p> <p>6. Before debriefing, ask:</p> <ul style="list-style-type: none"> <li>• <i>How could existing processes, procedures, or even the clinic structure where you work be improved to better support ALHIV with mental health problems?</i></li> </ul> <p>7. (optional) Encourage participation from the adolescent co-trainer. Ask the following questions to encourage his or her input and participation:</p> <ul style="list-style-type: none"> <li>• <i>How realistic are these case studies?</i></li> <li>• <i>What would you recommend, based on your own or your peers’ experience and perspective?</i></li> </ul>
<b>Debriefing</b>	<ul style="list-style-type: none"> <li>• A client’s mental health needs change over time and should be systematically assessed and considered at every visit.</li> <li>• Healthcare workers should watch for major signs of psychological and social distress, including behavioural and emotional problems, and impaired daily functioning in adolescent clients.</li> <li>• There are many challenges to providing mental health care in resource-limited settings, but there is a lot of support we can offer to adolescent clients and caregivers despite these barriers.</li> <li>• Healthcare workers can help clients and caregivers stay mentally healthy by offering counselling and emotional support, practical suggestions about to positively cope with life, and referring them to support groups, spiritual counsellors, and other groups.</li> </ul>

## **Exercise 2: Mental Health Assessment and Support: Role play and large group discussion**

### **Case Study 1:**

Mary is a 16-year-old client living with HIV. Mary tells you that her mother died last year. She says that she feels “stressed out” most of the time. She tells you that managing her schoolwork and taking care of her siblings is overwhelming, and she thinks that she will need to drop out of school. Mary also reports that she is often consumed by a sense of panic and feels like “her heart is leaping out of her chest.”

### **Key points for trainers: Mary**

- **What are the main mental health concerns for this client?**  
Mary is overwhelmed, and is contemplating dropping out of school, a decision that would affect the rest of her life. Note that her mother died last year (think anxiety).
- **What tools should the “healthcare worker” use to screen this client?**  
First, the “healthcare worker” should go through all of the questions

in the assessment of well-being screening tool (Table 6.1). Participants should fill in the screening tool as the “healthcare worker” administers it to Mary. Based on the case study alone we know the following:

**Assessment of well-being screening tool, results for Mary**

Mary’s response	Topic and key questions
? — need to ask	1. General mood and energy level
Feels stressed, which is daily functioning	2. Eating, sleeping, and daily functioning
Overwhelmed	3. Family and home
Overwhelmed	4. School or work
? — need to ask	5. Alcohol and drug use
? — need to ask	6. Support network and coping mechanisms

Given that she is having problems in 3 areas, and further screening questioning will likely reveal problems in other areas, we know that Mary needs further assessment.

- **What should the “healthcare worker” do next?**  
It looks like Mary’s constellation of symptoms resembles depression. As such, the “healthcare worker” should turn to “Appendix 6B: Screening and Management Tool for Depression” and ask Mary the questions in Sections 1 and 2.
- **What interventions would you recommend for this client?**  
Ask the large group to decide the appropriate intervention (sections 3, 4 or 5) of “Appendix 6B: Screening and Management Tool for Depression” based on Mary’s responses in Sections 1 and 2.
- **How would you manage this situation in your clinic? What specific actions would you, the healthcare worker, take? What services should be provided by the multidisciplinary care team?**  
Participants will discuss.
- **What other community-based resources should be provided to the client and caregiver?**  
Participants will discuss, but suggestions should include, for example, peer support, a support group, practical support (can an adult family member assist? How about social services?), other specific community- or faith-based groups.

**Case Study 2:**

Namwene is 13 years old and has been coming to the ART clinic since she was a small child. As a young child, she maintained good grades in school, and was described by her mother and grandmother as being helpful around the house. Recently, however, Namwene's relationship with her family has deteriorated, she is not eating or sleeping regularly, and she has run away from home twice in the past year. Namwene's mother suspects that she is using alcohol and possibly other drugs.

### Key points for trainers: Namwene

- What are the main mental health concerns for this client?**  
 Namwene’s relationship with her family is deteriorating, which means that her family support is deteriorating too. Any suspicion of alcohol or drug abuse is a red flag as well. Note: although it will be helpful to meet with Namwene together with her mother at the end of the counselling session; the mental health screening must be conducted in an individual counselling session with Namwene. Given the deteriorating relationship with her family, Namwene is unlikely to be completely honest at this point in time, if assessed in the presence of her mother.
- What tools should the “healthcare worker” use to screen this client?**  
 First, the “healthcare worker” should go through all of the questions in the “Table 6.1: Assessment of well being screening tool”. Again, ensure questionnaire is administered in an individual counselling session (not with the mother present). Participants should fill in the screening tool as the “healthcare worker” administers it to Namwene. Based on the case study alone we know the following:

Assessment of Well-Being screening tool, results for Namwene

Namwene’s response	Topic and key questions
? — need to ask	1. General mood and energy level
Not eating or sleeping regularly	2. Eating, sleeping, and daily functioning
Problems at home	3. Family and home
? — need to ask	4. School or work
Suspected by mother; need to ask client	5. Alcohol and drug use
Support within family deteriorating; need to ask about peer support	6. Support network and coping mechanisms

Given that she is having problems in 3, if not 4 areas, and further screening questioning will likely reveal problems in other areas, we know that Namwene needs further assessment.

- What should the “healthcare worker” do next?**  
 It’s hard to know what’s going on with Namwene. In this case it might make sense to start with part 1 in “Appendix 6A: Screening and

Management Tool for Anxiety”. If she says “no” to all 3 of those questions, go part 1 of “Appendix 6B: Screening and Management Tool for Depression”. If she responds “no” to all of those questions, then go onto part 2 of “Appendix 6D: Screening and Management Tool for Primary Psychotic Disorders”.

- **What interventions would you recommend for this client?**

It is difficult to know how this role play will go, as it depends on the actor playing the role of Namwene. But if Namwene says “no” to all of the questions in all 3 screening tools, then the underlying issue may be relationship between Namwene and her family or it could be a “disruptive behavioural disorder”. Intervention would require communication and counselling, initially in a one-to-one session then as a family. If Namwene answered “yes” for some of the questions in Appendix 6A, 6B or 6D, then follow the tool to guide decisions on intervention.

- **How would you manage this situation in your clinic? What specific actions would you, the healthcare worker, take? What services should be provided by the multidisciplinary care team?** Participants will discuss.

- **What other community-based resources should be provided to the client and caregiver?**

Participants will discuss, but suggestions should include, for example, peer support, a support group, referral for alcohol or drug abuse counselling, continued counselling within the clinic, referrals to a mental health professional and family counselling.

### **Case Study 3:**

Mumba is a 15-year-old boy who is perinatally infected with HIV. Accompanied by his grandmother, he comes to the clinic for a routine 3-month HIV visit with chronic fatigue, "difficulty remembering things," and gastrointestinal complaints. When you ask how he is feeling, he shrugs his shoulders but does not say anything. Mumba has a few friends, none of whom knows that he is living with HIV. His grandmother says he does not like to play and is withdrawn, preferring to just spend time alone. How would you proceed?

#### **Key points for trainers: Mumba**

- **What are the main mental health concerns for this client?**

Mumba has trouble remembering things, which could be a neuropsychiatric manifestation of HIV. He may also be depressed, in part because his undisclosed HIV status has left him feeling alone and different from his peers. Both of these problems could be interfering with adherence to his medications. What tools should the “healthcare worker” use to screen this client?

First, the “healthcare worker” should go through all of the questions in the “Table 6.1: Assessment of well being screening tool”. The questionnaire should be administered in an individual counselling

session (without the grandmother). Participants should fill in the screening tool as the “healthcare worker” administers it to Mumba. Based on the case study alone we know the following:

**Assessment of Well-Being screening tool, results for Mumba**

Mumba’s response	Topic and key questions
Low, chronic fatigue	1. General mood and energy level
? — need to ask	2. Eating, sleeping, and daily functioning
? — need to ask	3. Family and home
School — we don’t know, so need to ask; we do know that he has few friends	4. School or work
? — need to ask	5. Alcohol and drug use
Family — probably good, but need to ask; peer — probably poor but need to ask	6. Support network and coping mechanisms

Given that he is probably having problems in 3 areas, and further screening questioning will likely reveal problems in other areas, Mumba needs further assessment.

- **What should the “healthcare worker” do next?**

It looks like Mumba’s constellation of symptoms resembles depression. As such, the “healthcare worker” should turn to “Appendix 6B: Screening and Management Tool for Depression” and ask Mumba the questions in Sections 1 and 2. If the role play suggests (depending on how “Mumba” answers the questions), the “healthcare worker” may have to administer “Appendix 6C: Screening and Management Tool for Suicide Risk” as well.

- **What interventions would you recommend for this client?**

Ask the large group to decide the appropriate intervention (sections 3, 4 or 5) of “Appendix 6B: Screening and Management Tool for Depression” based on Mumba’s responses in Sections 1 and 2. Mumba’s problems with his memory suggest he may need a further assessment for cognitive problems related to HIV, although depression can also cause cognitive symptoms. Keeping in mind that many of Mumba’s complaints are somatic (for example, his GI complaints and chronic fatigue), his case needs to be discussed within the multidisciplinary team. He could have a medical condition, that when treated, could relieve many of the symptoms he has been experiencing. Just because this is a module on mental health....doesn’t mean that you should forget to think physical health

as well!

- **How would you manage this situation in your clinic? What specific actions would you, the healthcare worker, take? What services should be provided by the multidisciplinary care team?**  
Participants will discuss.

- **What other community-based resources should be provided to the client and caregiver?**

Participants will discuss, but suggestions should include, for example, peer support, a support group, family counselling, referral to mental health services, other specific community- or faith-based groups.

#### **Case Study 4:**

Peter, a 14-year-old boy who is perinatally infected with HIV, and his aunt arrive at the clinic for a routine check up. Peter is described by his aunt as being temperamental, hard to handle, and high-strung. His aunt also reports that he was suspended from school due to fighting with his classmates. She says he is also violent with his cousins at home and she does not know what to do to manage his behaviour. Peter was living with his mother until she died two years ago. He has not made a good adjustment to living with his aunt and feels she treats him differently than her own children. How would you proceed?

#### **Key points for trainers: Peter**

- **What are the main mental health concerns for this client?**

Peter is exhibiting disruptive behaviour both at home and at school, this can affect home life as well as the classroom dynamics. There could be many factors contributing to his difficult behaviour, including unresolved grief for the loss of his mother and feeling unwanted (whether justified or not) in his aunt's home.

- **What tools should the “healthcare worker” use to screen this client?**

First, the “healthcare worker” should go through all of the questions in the “Table 6.1: Assessment of well being screening tool”. The questionnaire should be administered in an individual counselling session (without the aunt). Participants should fill in the screening tool as the “healthcare worker” administers it to Peter. Based on the case study alone we know the following:

Assessment of Well-being screening tool, results for Peter

Peter's response	Topic and key questions
? — need to ask	1. General mood and energy level
? — need to ask	2. Eating, sleeping, and daily functioning
Many problems	3. Family and home
Many problems	4. School or work
? — need to ask	5. Alcohol and drug use
? — need to ask	6. Support network and coping mechanisms

Given that he is having problems in 2 areas and they are interfering with relationships at home and at school, we know that Peter needs further assessment.

- **What should the “healthcare worker” do next?**

Participants will suggest. They may want to go through the screening tools in Appendices 6A, 6B and 6D, which may or may not help to label his behaviour. Peter’s behaviour looks more like “disruptive behavioural disorder” rather than depression or anxiety. At the same time, his anger might come under better control by working with him and his aunt to improve their relationship and helping him become better integrated into his new home.

- **What interventions would you recommend for this client?**

Ask the large group to decide the appropriate intervention (see “Management and treatment for disruptive behavioural disorders:” on page 19).

- **How would you manage this situation in your clinic? What specific actions would you, the healthcare worker, take? What services should be provided by the multidisciplinary care team?**

Participants will discuss.

- **What other community-based resources should be provided to the client and caregiver?**

Participants will discuss, but suggestions should include, for example, peer support, a support group, family counselling, other specific community- or faith-based groups.

### **Case Study 5:**

Jane is an 18-year-old young woman who has been coming to the ART clinic for 2 years. Recently, she had missed a couple of visits and has appeared withdrawn and even tearful at the clinic. She also reports "drinking a little" and "not being very good at remembering to take all of her medications." You know that Jane has recently broken up with her boyfriend of 4 years, and she complains to you of sleep problems, having no energy, and says she has “lost hope” about her life. You notice that Jane has cut marks on her wrists. How would you proceed?

#### **Key points for trainers: Jane**

- **What are the main mental health concerns for this client?**

Jane is hopeless, cut marks on the wrist suggest past suicide attempts.

- **What tools should the “healthcare worker” use to screen this client?**

First, the “healthcare worker” should go through all of the questions in the Assessment of well-being screening tool (Table 6.1).

Participants should fill in the screening tool as the “healthcare worker” administers it to Jane. Based on the case study alone we know the following:

Assessment of Well-being screening tool, results for Jane

Jane's response	Topic and key questions
Withdrawn, no energy	1. General mood and energy level
Sleep problems	2. Eating, sleeping, and daily functioning
Recent break up with boyfriend; need to ask about family	3. Family and home
? — need to ask	4. School or work
Drinking a little; "a little" needs definition to assess for misuse	5. Alcohol and drug use
? — need to ask	6. Support network and coping mechanisms

Given that she is having problems in 4 of 6 areas, and further screening questioning will likely reveal problems in other areas, we know that Jane needs further assessment. The use of the word "lost hope" or "hopeless" should suggest to participants that this client is depressed. The suspected suicide attempt reinforces this suspicion.

- **What should the "healthcare worker" do next?**  
It looks like Jane' constellation of symptoms resembles depression. As such, the "healthcare worker" should turn to "Appendix 6B: Screening and Management Tool for Depression" and ask Jane the questions in Sections 1 and 2. Our suspicion is that Jane is also suicidal, as such administer "Appendix 6C: Screening and Management Tool for Suicide Risk" as well.
- **What interventions would you recommend for this client?**  
Ask the large group to decide the appropriate intervention (sections 3, 4 or 5) of "Appendix 6B: Screening and Management Tool for Depression" and section 11 of the "Appendix 6C: Screening and Management Tool for Suicide Risk."
- **How would you manage this situation in your clinic? What specific actions would you, the healthcare worker, take? What services should be provided by the multidisciplinary care team?**  
Participants will discuss.
- **What other community-based resources should be provided to the client and caregiver?**  
Participants will discuss, but suggestions should include, for example, counselling with a professional mental health professional, other specific community- or faith-based groups.



### **Trainer Instructions**

**Step 8:** Allow 5 minutes for questions and answers on this session.



### **Trainer Instructions**

Slides 57-59

**Step 9:** Ask participants what they think the key points of the module are. What information will they take away from this module?

**Step 10:** Summarise the key points of the module using participant feedback and the content below.

**Step 11:** Ask if there are any questions or clarifications



## **Module 6: Key Points**

- ALHIV face stressors associated with their disease, including loss and bereavement, cycles of wellness and poor health, barriers to care and community-based/social services. These stressors, combined with the normal stress of adolescence, means that ALHIV are especially susceptible to mental health problems.
- Healthcare workers should conduct a basic screening of mental health problems at every clinic visit, and ask caregivers about any changes in the client's behaviour at home, with friends, and/or at school. Healthcare workers should also observe behaviour during clinic visits to validate findings from the screening. Systematic screening for mental health problems and mental illness makes it possible to detect and treat problems early, potentially preventing the more serious issues.
- ALHIV may be at greater risk for mental health problems, such as depression. Anxiety is also very common in people living with HIV. Some clients will show signs and symptoms of both depression and anxiety. Anxiety and depression are common reactions to living with HIV, especially when people are not feeling well and do not get the support they need from family, friends, healthcare workers, and their community. Other common mental health issues include disruptive behavioural disorders, neurocognitive disorders, and "severe mental illness", which includes schizophrenia.
- Although there are barriers to providing mental health services in many settings (for example, insufficient resources, few treatment options, little data on ALHIV and mental health prevalence in sub-Saharan Africa), there are many concrete steps healthcare workers can do to support clients and caregivers.
- Healthcare workers can help clients and caregivers stay mentally healthy by offering counselling and emotional support, practical suggestions about how to positively cope with life, and referring them to support groups, spiritual counsellors, mental health professionals (if indicated), and other groups.

## Appendix 6A: Screening and Management Tool for Anxiety

✓	<b>Screening and management of anxiety in adolescents</b>	
	<b>1. Screen clients for anxiety by asking:</b>	
	<ul style="list-style-type: none"> <li>Do you experience palpitations (for example, heartbeat that is too fast)?</li> <li>Do you have a choking sensation or shortness of breath (hyperventilate)?</li> <li>Do you have clammy hands and sweat profusely?</li> </ul>	
	<b>2. If client responds YES TO 1 OR MORE of the above questions, ask:</b>	<b>3. If client says YES to this question:</b>
	1. Do the above symptoms last for more than 6 months on and off?	⇒ Client may have generalised anxiety disorder.
	2. Do you have a feeling of impending doom?	⇒ Client may have panic disorder.
	3. Do you experience intrusive thoughts (obsessions or repeated thoughts that always come back to your mind)?	⇒ Client may have obsessive compulsive disorder.
	4. Do you have repeated behaviour (compulsion or unwanted behaviours that seem impossible to stop or control) in an attempt to relieve the intrusive thoughts (obsessions or repeated thoughts that always come back to your mind)?	
	5. Do you have an unexplained or irrational fear or worry?	⇒ Client may have a phobia.
	6. Do you have vivid recollection or nightmares of a past trauma?	⇒ Client may have post-traumatic stress disorder.
	<b>4. Provide care and referrals:</b>	
	<ul style="list-style-type: none"> <li>Refer to a psychologist, psychiatrist, and mental health nurse if available, or provide basic counselling:</li> <li>Explain that these symptoms are part of an illness called anxiety, which is common and treatable.</li> <li>Recognise the client's distress by stating that you understand, and want to help.</li> <li>Identify current life problems and stressors, and focus on small steps the client might take to manage these problems.</li> <li>If client is taking efavirenz, make sure he or she is taking at bedtime. Symptoms usually resolve within first month of treatment.</li> <li>Advise client to discontinue use of substances that promote anxiety such as cigarettes and caffeinated beverages or stimulant drugs of abuse (e.g. chat)</li> </ul>	
	<b>5. Teach interventions to use during an anxiety attack (an episode of acute anxiety and feelings of panic):</b>	
	<ul style="list-style-type: none"> <li>Relaxation techniques: Sit upright in a chair with the feet flat on the ground and hands on the knees. Relax the whole body.</li> <li>Controlled breathing: When seated (as above), breathe in and hold breath for 10 seconds then breathe out and hold breath for 10 seconds. Repeat this until the palpitations stop and person feels relaxed.</li> <li>Re-breathing: If too agitated to sit still, then obtain a paper bag, cover nose and mouth with the bag, and breathe in and out of the paper bag until relaxed.</li> </ul>	
	If there is no improvement, refer to a psychiatrist at the nearest hospital.	

Adapted from: American Psychiatric Association. 2000. *Diagnostic and statistical manual of mental disorders* (4th ed., text rev.). Washington, DC: Author.

## Appendix 6B: Screening and Management Tool for Depression

✓	<b>Screening and management of depression in adolescents</b>	
	<b>1. Screen clients for depression by asking:</b>	
	• <i>Do you feel sad or depressed?</i>	
	• <i>Have you felt little interest or pleasure in doing things you usually enjoy?</i>	
	• <i>Do you have less energy than usual?</i>	
	<b>2. If client responds YES TO 1 OR MORE of the above questions, ask:</b>	
	Questions for client	Assessment
	<ul style="list-style-type: none"> <li>• <i>Over the past month, how would you say you've been sleeping: about the same as usual, better than usual or worse than usual?</i></li> <li>• <i>Is your sleep disturbed?</i></li> <li>• <i>When do you go to bed? When do you wake up? Do you sleep during the day?</i></li> </ul>	Experiencing disturbed sleep or sleeps most of the day? <input type="checkbox"/> Yes <input type="checkbox"/> No
	<ul style="list-style-type: none"> <li>• <i>Over the past month, would you say that you have been eating about the same amount as usual, more than usual or less than usual?</i></li> </ul>	Experiencing appetite loss or increase? <input type="checkbox"/> Yes <input type="checkbox"/> No
	<ul style="list-style-type: none"> <li>• <i>Over the past month, would you say your weight has been steady, or do you think you've gained or lost weight? (If possible, verify changes in weight with medical record.)</i></li> </ul>	Experiencing weight loss or gain? <input type="checkbox"/> Yes <input type="checkbox"/> No
	<ul style="list-style-type: none"> <li>• <i>Over the last month, would you say your <b>interest</b> in day-to-day activities has been about the same as usual, or have you been more interested or less interested than usual?</i></li> </ul>	Experiencing reduced interest in day-to-day activities? <input type="checkbox"/> Yes <input type="checkbox"/> No
	<ul style="list-style-type: none"> <li>• <i>Over the last month, would you say your <b>pleasure from</b> day-to-day activities has been about the same as usual, or have you received more pleasure or less pleasure from these activities than usual?</i></li> </ul>	Experiencing reduced pleasure in day-to-day activities? <input type="checkbox"/> Yes <input type="checkbox"/> No
	<ul style="list-style-type: none"> <li>• <i>Over the past month, has your desire for sex been about the same as usual, or has it increased or decreased? Or is this question not applicable to you?</i></li> </ul>	Experiencing decreased desire for sex? <input type="checkbox"/> Yes <input type="checkbox"/> No
	<ul style="list-style-type: none"> <li>• <i>Over the past month, would you say your ability to concentrate is about the same as usual, or is it better or worse?</i></li> </ul>	Experiencing poor concentration? <input type="checkbox"/> Yes <input type="checkbox"/> No
	<ul style="list-style-type: none"> <li>• <i>Over the past month, would you say that you have felt hopeless or helpless?</i></li> </ul>	Feelings of hopelessness and helplessness? <input type="checkbox"/> Yes <input type="checkbox"/> No
	<ul style="list-style-type: none"> <li>• <i>Over the past month, have you considered killing yourself?</i></li> </ul>	Thoughts of suicide or death?

<ul style="list-style-type: none"> <li>Over the past month, would you say that you have been thinking a lot about death?</li> </ul>	<input type="checkbox"/> Yes <input type="checkbox"/> No
If client has suicidal thoughts, administer the screening tool for suicide.	
<ul style="list-style-type: none"> <li>Do you hear voices inside your head or ears (auditory hallucinations)?</li> <li>Do you see things others do not see (visual hallucinations)?</li> <li>Do you have suspicions (paranoid delusions) that people around you feel are excessive?</li> </ul>	Delusions or hallucinations? <input type="checkbox"/> Yes <input type="checkbox"/> No
If client is experiencing delusions or hallucinations, administer the screening tool for psychotic disorders.	
<b>Total number of "yes" responses:</b>	
<b>3. If the client responded "yes" to 5 OR MORE of the above questions, and symptoms have lasted MORE THAN 2 WEEKS, then the person may have Major Depression.</b>	
Refer to counselling services if available, or provide basic counselling: <ul style="list-style-type: none"> <li>Explain that these symptoms are part of an illness called depression, which is common and treatable.</li> <li>Recognise the client's distress by stating that you understand and want to help.</li> <li>Identify current life problems and stressors, and focus on small steps the client might take to positively cope and manage these problems.</li> <li>Refer to peer support group, if available.</li> </ul>	
If client is taking efavirenz, make sure he or she is taking it at bedtime. Symptoms usually resolve within first month of treatment.	
<b>4. If the client responded "yes" to LESS THAN 5 of the above symptoms or has experienced MORE THAN 2 MONTHS OF BEREAVEMENT with functional impairment:</b>	
<ul style="list-style-type: none"> <li>Offer ongoing supportive counselling to counter depression.</li> <li>Follow up in 1 week.</li> </ul>	
<b>5. If the client responded "yes" to LESS THAN 5 of the above symptoms, but is ABLE TO FUNCTION day-to-day:</b>	
<ul style="list-style-type: none"> <li>Counsel and assure psychosocial support.</li> </ul>	

Adapted from: American Psychiatric Association. 2000. *Diagnostic and statistical manual of mental disorders* (4th ed., text rev.). Washington, DC: Author.

## Appendix 6C: Screening and Management Tool for Suicide Risk

The **SAD PERSONS** scale is an acronym used as a mnemonic device for a suicide risk clinical assessment tool. This tool that appears below was adapted by Gerald A. Juhnke in 1996 for use with children and adolescents.

✓	Screening tool for suicide	
	Questions for client	Response
<b>S</b>	<b>1. Sex</b>	
	Tick “yes” if client is male.	<input type="checkbox"/> Yes <input type="checkbox"/> No
<b>A</b>	<b>2. Age</b>	
	<ul style="list-style-type: none"> <li>How old are you?</li> </ul> Tick “yes” if client is older than 15 years.	<input type="checkbox"/> Yes <input type="checkbox"/> No
<b>D</b>	<b>3. Depression or affective disorder</b>	
	Tick “yes” if client is depressed. (See Screening Tool for Depression.)	<input type="checkbox"/> Yes <input type="checkbox"/> No
<b>P</b>	<b>4. Previous suicide attempt or psychiatric care</b>	
	<ul style="list-style-type: none"> <li>Have you ever tried to commit suicide?</li> </ul> Tick “yes” if client has previously tried to kill him or herself.	<input type="checkbox"/> Yes <input type="checkbox"/> No
<b>E</b>	<b>5. Ethanol or drug abuse</b>	
	<ul style="list-style-type: none"> <li>How often do you drink alcohol? How many drinks do you have?</li> <li>What other recreational drugs do you use? How often do you use them?</li> </ul> Tick “yes” if client abuses alcohol or drugs.	<input type="checkbox"/> Yes <input type="checkbox"/> No
<b>R</b>	<b>6. Rational thinking loss (psychosis)</b>	
	<ul style="list-style-type: none"> <li>Do you hear voices inside your head or ears (auditory hallucinations)?</li> <li>Do you see things others do not see (visual hallucinations)?</li> <li>Do you have suspicions (paranoid delusions) that people around you feel are excessive?</li> <li>Do you have periods of abnormal (disorganised) behaviour that cause concern to the people around you?</li> </ul> Tick “yes” if client has experienced psychosis.	<input type="checkbox"/> Yes <input type="checkbox"/> No
<b>S</b>	<b>7. Social support lacking</b>	
	<ul style="list-style-type: none"> <li>Have there been any major changes in your family over the past 3–5 years? (parental death, death of another family member, divorce, re-marriage)</li> <li>Have you currently broken up with a partner or close friend?</li> </ul> Tick “yes” if client either lacks social support, or has experienced recent losses to their support system.	<input type="checkbox"/> Yes <input type="checkbox"/> No
<b>O</b>	<b>8. Organised plan or attempt</b>	
	<ul style="list-style-type: none"> <li>Do you have a plan for how you want to commit suicide?</li> </ul>	<input type="checkbox"/> Yes <input type="checkbox"/> No

	Tick “yes” if client has a plan.		
<b>N</b>	<b>9. Negligent parenting, significant stressors, suicidal modelling by parents or siblings</b>		
	<ul style="list-style-type: none"> <li>• <i>How is your relationship with your parents? Did your parents ever hit you?</i></li> <li>• <i>Has anyone else in your family committed suicide?</i></li> </ul> Tick “yes” if client has a history of neglect, abuse, trauma, chaotic lifestyle, or history of suicidal behaviours in the family.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
<b>S</b>	<b>10. School problems</b>		
	<ul style="list-style-type: none"> <li>• <i>How is school going?</i></li> <li>• <i>How many friends would you say you have at school?</i></li> <li>• <i>Is there anyone at school that bullies you, that is, makes fun of you, hits or threatens you?</i></li> </ul> Tick “yes” if client has a history of chronic conflict with peers and problems associated with school.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
<b>Total number of “yes” responses:</b>			
<b>11. Interpreting scores</b>			
Total number of “yes” responses:			
0–2	No real problems, provide counselling*, send home but set appointment for follow up		
3–4	Provide counselling*, send home but check frequently		
5–6	Provide counselling*, refer to psychologist or consider inpatient depending on safety level and follow-up capability		
7–10	Refer for hospitalisation (voluntary or involuntary)		
*Counselling:			
<ul style="list-style-type: none"> <li>• Recognise the client’s distress by stating that you want to help.</li> <li>• Identify current life problems and stressors, and focus on small steps the client might take to manage these problems.</li> <li>• Encourage client to resist being pessimistic and self-critical.</li> <li>• Do not leave the client alone.</li> <li>• Remove any harmful objects from the home.</li> <li>• If the underlying problem is depression, manage according to the guidelines in “Appendix 6B: Screening and Management Tool for Depression”.</li> <li>• Before giving medication, ensure relatives are available to store the medication and administer it to the client — at least during the first 2 weeks of treatment. Be aware that tricyclic antidepressants are quite dangerous in overdose.</li> <li>• Frequent consultations and counselling are advised when there is no other social support.</li> </ul>			

Adapted from: American Psychiatric Association. 2000. *Diagnostic and statistical manual of mental disorders* (4th ed., text rev.). Washington, DC: Author.

## Appendix 6D: Screening and Management Tool for Primary Psychotic Disorders

✓	<b>Screening and management of psychotic disorders in adolescents</b>
	<b>1. Rule out delirium</b>
	<p>Delirium is a serious medical condition that can also present with delusions, hallucinations (often visual) and agitation. Suspect delirium if any the following are present:</p> <ul style="list-style-type: none"> <li>• Rapid onset and changes in consciousness (for example agitated one minute and sleepy the next).</li> <li>• Confusion and inattention</li> <li>• Poor orientation to time, place or person</li> <li>• Patient appears to be physically ill</li> <li>• History of recent head trauma</li> <li>• History of alcohol and/or other drug intoxication or withdrawal</li> <li>• History of seizure disorder</li> <li>• Fever — an agitated adolescent who is febrile should always be presumed to be medically ill.</li> </ul> <p>Adolescents suspected of delirium should be referred for urgent medical evaluation and treatment.</p>
	<b>2. If delirium is not suspected, screen clients for psychotic disorders by asking:</b>
	<ul style="list-style-type: none"> <li>• <i>Do you hear voices inside your head or ears (auditory hallucinations)?</i></li> </ul>
	<ul style="list-style-type: none"> <li>• <i>Do you see things others do not see (visual hallucinations)?</i></li> </ul>
	<ul style="list-style-type: none"> <li>• <i>Do you have suspicions (paranoid delusions) that people around you feel are excessive?</i></li> </ul>
	<ul style="list-style-type: none"> <li>• <i>Do you have periods of abnormal (disorganised) behaviour that cause concern to the people around you?</i></li> </ul>
	<b>3. If the client responded “yes” to 1 OR MORE of the above questions, observe whether:</b>
	<ul style="list-style-type: none"> <li>• The client is unkempt</li> <li>• The behaviour is bizarre</li> <li>• The thoughts do not make sense or are completely unrealistic</li> <li>• The patient is angry, agitated or suspicious</li> <li>• The client talks to him/herself, or appears to be talking to people who are not there.</li> </ul>
	<b>4. If the client has symptoms of any one of the above:</b>
	<ul style="list-style-type: none"> <li>• Consider giving antipsychotic medications.</li> <li>• Provide basic counselling</li> </ul>
	<b>5. If symptoms get worse :</b>
	<ul style="list-style-type: none"> <li>• Reassess for delirium</li> <li>• Refer to a psychiatrist or mental health nurse for assessment</li> </ul>

Adapted from: American Psychiatric Association. 2000. *Diagnostic and statistical manual of mental disorders* (4th ed., text rev.). Washington, DC: Author.

## References and Resources

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- <sup>1</sup> Bush-Parker, T. 2000. *Perinatal HIV: Children with HIV Grow Up*. Focus: A Guide to AIDS Research and Counseling; 15(2):1–4.
- <sup>2</sup> Frank, L. 2006. *Adolescents, HIV, and Mental Health*. AETC National Resource Center and AETC Adolescent HIV/AIDS Workgroup.
- <sup>3</sup> Mellins, C., Brackis-Cott, E., Leu, C., Elkington, K., Dolezal, C., Wiznia, A., McKay, M., Bamji, M., Abrams, E.J. 2009. *Rates and Types of Psychiatric Disorders in Perinatally Human Immunodeficiency Virus-Infected Youth and Seroreverters*. Journal of Child Psychology and Psychiatry ; 50(9):1131–1138.
- <sup>4</sup> Mellins C.A., Brackis-Cott, E., Dolezal, C., Abrams, E.J. 2006. *Psychiatric Disorders in Youth with Perinatally Acquired Human Immunodeficiency Virus Infection*. Pediatric Infectious Disease Journal; 25(5):432–437.
- <sup>5</sup> American Psychiatric Association. 2000. *Diagnostic and statistical manual of mental disorders* (4th ed., text rev.). Washington, DC: Author.
- <sup>6</sup> Frank, L. 2006. *Adolescents, HIV, and Mental Health*. AETC National Resource Center and AETC Adolescent HIV/AIDS Workgroup.
- <sup>7</sup> Frank, L. 2006. *Adolescents, HIV, and Mental Health*. AETC National Resource Center and AETC Adolescent HIV/AIDS Workgroup.
- <sup>8</sup> Colton, T., Dillow, A., Hainsworth, G., Israel, E., & Kane, M. 2006. *Community home-based care for people and communities affected by HIV/AIDS: A comprehensive training course for community health workers*. Watertown, MA: Pathfinder International.



# Module 7 Providing Disclosure Counselling and Support



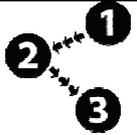
**Total Module Time:** 230 minutes (3 hours, 50 minutes)

## Learning Objectives

**After completing this module, participants will be able to:**

- Apply a developmental approach to the process of disclosure preparation.
- Support caregivers to understand the importance of disclosure and to continue to move through the disclosure process with adolescents.
- Provide counselling and support to adolescents on disclosing their HIV status to others.

## Methodologies



- Interactive trainer presentation
- Large group discussion
- Start-stop role play using case studies
- Role play using case studies

## Materials Needed



- Slide set for Module 7
- Flip chart and markers
- Tape or Bostik
- Participants should have their Participant Manuals. The Participant Manual contains background technical content and information for the exercises.

## References and Resources



- Adherence Networking Group. 2006. *Kids Count: Guide for Trainers, Children's ART Adherence Resource Pack*.
- Colton, T., Costa, C., Twyman, P., Westra, L., and Abrams, E. 2009. *Comprehensive Peer Educator Training Curriculum, Trainer Manual, Version 1.0.*, International Center for AIDS Care and Treatment Programs.
- The South to South Partnership for Comprehensive Family HIV Care and Treatment Program; International Center for AIDS Care and Treatment Programs; François Xavier Bagnoud, University of Medicine and Dentistry of New Jersey. 2010. "HIV Care & Treatment Training Series", Module 6: Disclosure Process for Children Ages 3 to 18 Living with HIV.



	<ul style="list-style-type: none"><li>• Mellins, C., Brackis-Cott, E., Dolezal, C., Richards, A., Nicholas, S., Abrams, E. 2002. <i>Patterns of HIV Status Disclosure to Perinatally HIV-Infected Children and Subsequent Mental Health Outcomes</i>. <i>Clinical Child Psychology and Psychiatry</i>; 7:101-114.</li></ul>
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**Advance Preparation**



- Read through the entire module and ensure that all trainers are prepared and comfortable with the content and methodologies.
- Exercises 1 and 2 require advance preparation.
- Review the appendix and ensure all trainers are comfortable integrating it into the module.

### **Session 7.1: The Disclosure Process: A Developmental Approach**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation and large group discussion	25 minutes
Questions and answers	5 minutes
Total Session Time	30 minutes

### **Session 7.2: Disclosure Preparation, Counselling, and Support for Caregivers**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation and large group discussion	60 minutes
Exercise 1: Supporting Caregivers with the Disclosure Process: Start-stop role plays and large group discussion	45 minutes
Questions and answers	5 minutes
Total Session Time	110 minutes

### **Session 7.3: Disclosure Counselling and Support for Adolescents Who Know Their Status**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation	25 minutes
Exercise 2: Supporting ALHIV with the Disclosure Process: Role plays and large group discussion	50 minutes
Questions and answers	5 minutes
Review of key points	10 minutes
Total Session Time	90 minutes

## Session 7.1

# The Disclosure Process: A Developmental Approach



**Total Session Time:** 30 minutes



### Trainer Instructions

Slides 1-4

**Step 1:** Begin by reviewing the Module 7 learning objectives and the session objective, listed below.

**Step 2:** Ask participants if there are any questions before moving on.

### Session Objective

**After completing this session, participants will be able to:**

- Apply a developmental approach to the process of disclosure preparation.



### Trainer Instructions

Slides 5-9

**Step 3:** Begin by asking participants to offer examples that illustrate their personal experiences with paediatric and adolescent disclosure and discuss their perspectives about disclosure in clinical practice:

- *What have been some of your personal experiences and challenges working with caregivers who need assistance disclosing to their children/adolescents? With ALHIV who know their status and need assistance disclosing to others?*

**Step 4:** Ask the following questions to facilitate discussion and record key points on a flip chart:

- *What is meant by the term “disclosure?” How does this translate into the local language?*
- *What do you think is meant by the phrase, “Disclosure is an ongoing process?”*
- *What is meant by a “developmental approach” to disclosure? What are some examples of this with younger and older adolescents?*
- *What key points about disclosure are important for younger and older adolescents to know?*

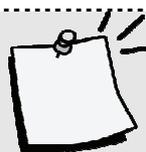
Take 5–10 minutes to review with participants “Appendix 7A:

Guidance for Developmentally Appropriate Disclosure”, for the moment, just focus on the first 2 columns labelled:

- Age group characteristics
- Disclosure considerations and guidance

**Step 5:**

(optional) If he or she is willing and comfortable, ask the adolescent co-trainer to share his or her experiences and challenges with the disclosure process.



**Make These Points**

- Disclosure is an ongoing process.
- Disclosure of HIV status to adolescents is a process that should begin early in life by addressing the child’s health status and the need for medication, clinic visits, and blood tests in very simple terms without necessarily using the word “HIV” or names of medications.
- Disclosure is not a one-time event and ALHIV and caregivers need ongoing support for disclosure.
- Ideally, adolescent clients will already know about their HIV status and caregivers will be well into the disclosure process. However, some adolescent clients, especially those on the younger end of the adolescent spectrum, may not be fully disclosed to.
- Disclosure of diagnosis to an HIV-infected adolescent should incorporate a developmental approach. It should be tailored to the adolescent’s cognitive ability, developmental stage, clinical status, and social circumstances.

## **Overview of Disclosure and ALHIV<sup>1,2</sup>**

### **What is disclosure?**

Disclosure should be seen as a process — not a one-time event — of telling an adolescent that he or she has HIV, and helping the young person to understand what this means. It can also mean helping an ALHIV to disclose his or her HIV status to others. It is a 2-way conversation that involves:

- Speaking truthfully with the adolescent (and sometimes the caregiver), over time, about his or her illness,
- Disclosing the specific diagnosis at a time appropriate to the young person’s needs or helping the caregiver to do so, and
- Helping the young person prepare to disclose to others and providing follow-up support during the process.

**Through the process, the young person should come to know about:**

- The diagnosis, the infection and disease process, and health changes that could occur.
- Strategies to prolong a healthy life (in particular adherence to ART) and responsibilities now and in the future.
- How to cope with the possible negative reactions of others.

**Developmental approach to disclosure for adolescents**

- Decisions about when to start talking to children about their health will be determined by the readiness of the caregiver, as well as by the developmental stage of the child.
- Each phase of an adolescent’s development (from early to late adolescence) has characteristic features. Understanding an adolescent’s developmental stage and needs is vital to disclosure. An adolescent’s understanding of the process will evolve as their brain becomes more equipped to absorb complex material and as emotional maturity level increases.
- Understanding adolescent development will help healthcare workers and caregivers better guide the disclosure process for adolescents, ensuring that appropriate information is presented when the young person is able to cope with it.
- It is important to note that developmental stages are associated with approximate ages; however, just because a young person is a certain age does not necessarily mean that their development is the same as those of others in that age group. Therefore, it is also essential to follow up with questions to assess the young person’s understanding.

See “Appendix 7A: Guidance for Developmentally Appropriate Disclosure” for additional information.



**Trainer Instructions**

**Step 6:** Allow 5 minutes for questions and answers on this session.

## Session 7.2      Disclosure Preparation, Counselling, and Support for Caregivers

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**Total Session Time:** 110 minutes (1 hour, 50 minutes)



### **Trainer Instructions**

Slides 10-11

**Step 1:** Begin by reviewing the session objective listed below.

**Step 2:** Ask participants if there are any questions before moving on.

### **Session Objective**

**After completing this session, participants will be able to:**

- Support caregivers to understand the importance of disclosure and to continue to move through the disclosure process with adolescents.



### **Trainer Instructions**

Slides 12-20

**Step 3:** Discuss why it is important for all adolescents to know their HIV status. Next, discuss how healthcare workers can help parents and caregivers prepare for disclosure to their children and give follow-up support to the family after disclosure. Ask participants the following questions to facilitate discussion:

- *Do you think it is important for ALHIV to know their HIV status? Why/why not?*
- *What are some of the reasons adults, and even healthcare workers, are hesitant to/may not want to disclose to the adolescent?*
- *What is the difference between partial and full disclosure? How does this apply to ALHIV?*
- *What challenges have you encountered with adolescents who do not know their status? How can healthcare workers prevent these challenges?*

**Step 4:** Debrief by explaining that healthcare workers should start talking about disclosure with caregivers WELL before the child is an adolescent. We know there are many challenges associated with the disclosure process, and that it is a

complicated and sensitive process. Healthcare workers play an important role in helping families negotiate these challenges and barriers.

**Step 5:** (optional) If he or she is willing and comfortable, ask the adolescent co-trainer to share his or her own experiences about the process of learning his or her HIV status.



### **Make These Points**

- Disclosure of a child's HIV status is one of the most sensitive issues for caregivers. It is particularly difficult for caregivers who are themselves living with HIV, especially where the young person's status is a result of mother-to-child transmission.
- All young people have the right to participate in decision making about their own health care. Knowledge of their status may also help to promote adherence to treatment, while not knowing or having a confused understanding may cause difficulties with adherence.
- There are multiple barriers to supporting disclosure in the clinic setting. Most healthcare worker barriers can be addressed through training, peer support and supportive supervision. Most caregiver barriers can be addressed, at least in part, with healthcare workers counselling and support.
- The disclosure process with perinatally infected children should begin early, by at least of 6 years of age, and more information and details given as the child grows and develops. It is recommended that young people are fully disclosed to by the age of 10–14, but this will depend on the individual child and family.

## **Disclosure of HIV Status to ALHIV**

To improve the chances that the disclosure process proceeds as smoothly as possible, healthcare workers should start talking about disclosure with caregivers **WELL** before the child is an adolescent (it is recommended that partial disclosure — see “Partial and Full Disclosure” on page 12 — begin by the time the child is 6 years old). Ideally, the young person will already know about their HIV status by the time he or she is an adolescent. However, there are challenges associated with the disclosure process and healthcare workers play an important role in helping families work through these barriers.

What are the reasons to disclose a child's HIV status?

- All children/adolescents have a right to know about their own health care.

- Adolescents often want and ask to know what is wrong. Adolescents are observant, smart, and curious.
- ALHIV who have not been disclosed to may have frightening or incorrect ideas about their illness, feel isolated and alone, learn their HIV status by mistake, or have poor adherence.
- Disclosure may help improve social functioning and school performance due to a decrease in stress.
- When adolescents learn about their status directly from their caregivers, it can provide comfort and reassurance. Too often, adolescents overhear healthcare workers and caregivers talking about their health as if they are not in the room.
- Children and adolescents are exposed to unintended “clues” of their diagnosis, for example, HIV-related signs on the walls of the clinics they attend, etc.
- Disclosure for orphaned or other vulnerable and most-at-risk adolescents is especially critical, because they may wonder why they have lost a parent or been rejected by the family. Disclosure will also help them seek the services they need, especially those who do not have regular caregivers.
- Adolescents who know their HIV status can access HIV care and treatment, take an active role in their care and treatment plan and, when old enough, take steps to live positively, adhere to treatment, and prevent new infections.
- Disclosure affects the mental health of the adolescent and caregiver. Non-disclosure does not protect the young person. Levels of anxiety, depression and low self-esteem have been shown to be higher in adolescents who have not been disclosed to. Parents who have disclosed the status to their children also experience better mental health outcomes (for example, less depression than those who do not).

## **Barriers to Disclosure**

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### **Healthcare worker barriers**

Healthcare workers may also find it difficult to discuss HIV infection and disclosure with caregivers and adolescents. Healthcare workers experience some of the same barriers experienced by caregivers, such as not knowing where to start or being concerned about harming the adolescent (see next section). Training is essential to equip healthcare workers to support caregivers and adolescents throughout the disclosure process. Additionally, asking the advice of other healthcare workers who have been through this process with caregivers and observation of more experienced healthcare workers is important. Additionally, knowing the backgrounds, limitations and resources of caregivers will help to improve healthcare workers' sense of mastery and comfort assisting and supporting the disclosure process. Other barriers are listed in Table 7.1 along with suggested solutions for each barrier.

**Table 7.1: Solutions to healthcare worker barriers to disclosure**

Healthcare worker barrier	Suggested solution
<b>Healthcare worker may be unsure about their role or think that the process of disclosure is not their responsibility</b>	All members of the multidisciplinary team can support the process of disclosure in various ways. Discussing and defining healthcare workers' roles in the process of disclosure can promote effective coordination among the team members involved.
<b>Differences of opinion between healthcare workers and caregivers — or among healthcare workers.</b>	<p>It can be challenging when the healthcare worker thinks that the adolescent needs to understand their HIV diagnosis but the caregiver is not ready to start or move ahead with the disclosure process.</p> <p>When conflicts about disclosure arise, it is helpful to remember that disclosure is a process that takes time. Careful assessment of barriers to disclosure and working with the caregiver is often required to agree on what, when and how to disclose to the adolescent. It is always important to remember that the decision of the caregiver should be respected.</p>

### Caregiver barriers

Caregivers may not want to disclose their children's HIV status for a number of reasons, all of which are valid. Healthcare workers should never judge a caregiver for their unwillingness to disclose, for their fears about disclosure, or their "performance" during the disclosure process. Table 7.2 includes a partial listing of caregiver barriers alongside suggested healthcare worker responses for each barrier.

**Table 7.2: Addressing caregiver barriers to disclosure**

Caregiver barrier	Suggested healthcare worker response
<b>Fear that disclosure will cause psychological harm</b>	<p>Those who fear that disclosure will cause psychological harm, may assume that disclosure could:</p> <ul style="list-style-type: none"> <li>• Reduce the adolescent's will to live</li> <li>• Make the adolescent think they are not normal</li> <li>• Strip adolescents of their happiness — an unconscionable gamble for caregivers who believe that children/adolescents are supposed to be happy</li> </ul> <p>Healthcare workers can:</p> <ul style="list-style-type: none"> <li>• Reassure caregivers that contrary to common assumptions, studies have shown that there are</li> </ul>

	<p>positive psychological benefits when they are appropriately aware of their illness. Studies suggest that young people who know their HIV status have higher self-esteem than young people who are unaware of their status. Parents who have disclosed the status to their children also experience better mental health outcomes (for example, less depression than those who do not).</p> <ul style="list-style-type: none"> <li>• Connect caregivers to others who have gone through the process of disclosure (peer support) and are willing to share their experiences.</li> </ul>
<b>Concern that topic is too complicated for the adolescent to understand</b>	<p>Reassure caregivers that the healthcare worker will work with them to ensure that all disclosure-related conversations are appropriate to the adolescent's age and developmental status (for example, understanding, emotional maturity, etc). The aim of these many conversations, that will take place over many years, is to help the adolescent become "appropriately aware of his or her illness", not to explain everything all at once.</p>
<b>Unsure of where to start or how to respond to questions</b>	<p>The healthcare worker can begin talking to the caregiver very early about the disclosure process — long before anything is said to the adolescent. This will help the caregiver make a plan for where, when and how to begin the process of disclosure.</p>
<b>Lack of knowledge/comfort with topic</b>	<p>The healthcare worker should:</p> <ul style="list-style-type: none"> <li>• Provide caregivers with the background information they need to discuss HIV with their children. Ensure the caregiver's questions are answered throughout the disclosure process.</li> <li>• Provide the caregiver with possible answers to the adolescent's anticipated questions.</li> <li>• Role play various disclosure scenarios to give the caregiver practise.</li> <li>• Decide with the caregiver what is appropriate/necessary to tell the adolescent at each stage of development, given the adolescent's level of understanding.</li> </ul>
<b>Fear of stigma and discrimination against adolescent and other family members</b>	<p>Disclosure of HIV status is complicated by the fact that HIV infection brings with it stigma and discrimination that are rarely associated with other diseases. Healthcare workers can reduce this stigma and discrimination within family systems by:</p> <ul style="list-style-type: none"> <li>• Supporting caregivers to provide guidance to their adolescents about disclosure, and with whom they may safely speak about their illness (confidentiality within the home and community).</li> <li>• Suggesting to caregivers that they identify one or</li> </ul>

	<p>more trustworthy people with whom the adolescent is regularly in contact (other than the healthcare worker) to be a “safe” person — one with whom the child can discuss his or her HIV status, concerns and treatment. If adolescents have one “safe” person they will be less likely to disclose inappropriately.</p> <ul style="list-style-type: none"> <li>• Involving caregivers and other family members early in the disclosure process, to ensure misinformation about HIV is corrected early on.</li> <li>• Referring the adolescent and caregivers to support groups where others can provide advice on dealing with stigma.</li> <li>• Maintaining a continuous open line of communication with the adolescent to help him or her deal with their changing feelings about HIV and negative reactions from society.</li> </ul>
<p><b>Parent guilt regarding transmission</b></p>	<p>Healthcare workers should remember that disclosure of HIV status to adolescents is often a family issue as it is related to one or both of the parents’ infection status. Healthcare workers can help parents deal with the shame or guilt of passing on HIV to their children by encouraging them to:</p> <ul style="list-style-type: none"> <li>• Understand that they should not blame themselves for getting HIV.</li> <li>• Take care of themselves, for example, go to the clinic regularly and take their medication. Taking specific actions to improve their health will reduce the sense of powerlessness that may accompany feelings of guilt.</li> <li>• Model positive living for their children. Healthy behaviours reflect a positive attitude towards life, thereby encouraging children to also see life with optimism.</li> </ul>

Adapted from: The South to South Partnership for Comprehensive Family HIV Care and Treatment Program; International Center for AIDS Care and Treatment Programs; François-Xavier Bagnoud Center, University of Medicine and Dentistry of New Jersey. 2010. "HIV Care & Treatment Training Series", Module 6: Disclosure Process for Children Ages 3 to 18 Living with HIV.

## **Partial and Full Disclosure**

Disclosure to adolescents depends on their stage of development: Young children may only need to know that they are sick and have to go to the doctor and take medicines to feel better (partial disclosure); older children/adolescents should know that they have HIV, understand the disease and the medications, and actively participate in their own care and treatment (full disclosure). As an adolescent develops, caregivers and healthcare workers should eventually move from partial to full disclosure,

gradually helping the young person to understand and cope with knowing their diagnosis.

### **Partial disclosure:**

Children develop the ability for logical thinking around 6 years of age. It is at this time that they are able to begin to understand the concept of illness and what causes it; partial disclosure may therefore be considered around this age, particularly if the child has started asking questions related to his or her health. Partial disclosure:

- Refers to giving a child information about his or her illness without using the actual words “HIV” or “AIDS”.
- Helps move the disclosure process forward and prepares the child/adolescent and caregivers for full disclosure later on.
- Is an effective strategy to help caregivers who do not yet feel ready to use the terms “HIV” and “AIDS” or for caregivers of young children who are not ready for full disclosure.
- Is useful for building a context in which full disclosure can be more meaningful for a child.

### **Full disclosure:**

“Full disclosure” is when a child/adolescent is specifically told that he or she is HIV-infected and given more HIV-related details, for example, how it is transmitted, how the child might have contracted it. Families and caregivers must decide at what point full disclosure is necessary. It is generally recommended that children are fully disclosed to when they are developmentally ready to receive the information, typically between the ages of 10–14<sup>3</sup>. A particularly important indication that full disclosure should be considered is when the child starts asking specific questions about his or her illness, for example, how did he or she get the sickness, and no longer seems satisfied with the responses previously received.

Full disclosure is easier for the child/adolescent if they have been partially disclosed to over time, understand some basics about their health and their care and medicines, and have been supported throughout the disclosure process.



#### **Trainer Instructions**

Slides 21-27

#### **Step 6:**

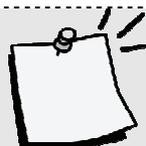
Now that the complexities and challenges to the disclosure process have been discussed, facilitate a discussion about how healthcare workers can provide disclosure support to caregivers and adequately prepare them for disclosure to their children. Record the responses on a flip chart.

- *How can healthcare workers help parents and caregivers prepare for disclosure to their children?*
- *What is the healthcare worker’s role in the process?*
- *What questions would you ask to assess a caregiver’s*

*readiness to disclose to their child and determine the level of support that they might require?*

- *How would you respond if a caregiver is not ready to start or move forward in the disclosure process?*

**Step 7:** Review the guidelines for assisting caregivers in disclosure, including Table 7.3, which lists key questions to assess caregiver support needs.



### **Make These Points**

- The healthcare worker's role is not to take over from or stand in for the caregiver, but rather to support the caregiver and facilitate the conversation between caregiver and adolescent.
- Healthcare workers can support the disclosure process by preparing and educating caregivers, and planning follow-up support for both caregivers and adolescents. All adolescents who are disclosed to need to be able to continue to ask questions and discuss their feelings with caregivers and healthcare workers.
- If the caregiver is not ready to disclose, the process cannot be forced.
- Validation of caregivers' concerns can foster a partnership and prevent the development of an adversarial relationship between the members of the healthcare team and caregivers.

## **Providing Disclosure Support to Caregivers**

General considerations when disclosing to adolescents:

- All adolescents have a right to know about their own health. We must work with caregivers to encourage disclosure.
- When we disclose to adolescents, we must consider the needs, feelings and beliefs of the adolescents, caregivers, as well as the specific family situation.
- We need to involve all of the adolescent's caregivers and make sure everyone has the same messages. Everyone should know how and when the young person will be disclosed to and what the ongoing disclosure plan is. There are challenges when a young person has many caregivers or when the caregivers change. Healthcare workers help by asking about all of the caregivers and family members, and by making sure they are given support throughout the disclosure process.
- Keep in mind that disclosure to adolescents depends on their stage of development:
  - Young adolescents may only need to know that they are sick, and must go to the doctor and take medicines to feel better.

- Older adolescents should know that they have HIV, understand the disease and the medications, and actively participate in their own care and treatment.
- Plan for follow-up support to the family, including the young person, after disclosure.
- Healthcare workers should work with caregivers to develop a disclosure plan that incorporates the concerns and meets the individualised needs of all family members, including siblings and other relatives, if applicable.
- Healthcare workers should never make judgements about how the caregiver ‘performs’ during the disclosure process.
- Healthcare workers should always apply the principle of shared confidentiality within the multidisciplinary care team when discussing disclosure with clients and caregivers.
- **Remember: Disclosure to adolescents is not a one-time event and will require many conversations over time.**

## **Healthcare Worker Role in Disclosure**

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The role of the healthcare worker in the disclosure process:

- Usually, the primary caregiver should be the person to disclose to the child. Sometimes, caregivers ask for help with the process. A healthcare worker can assist, first by preparing the caregiver and then, if asked, being present when the caregiver talks with the child. In some cases, the healthcare worker may be asked to take a more active role in the disclosure process.
- Healthcare workers may or may not be involved in the discussions during which the adolescent is disclosed to — some caregivers prefer to do this at home, but some may prefer to come to the clinic where they can get assistance from the healthcare worker.
- The role of the healthcare worker is to encourage open dialogue about disclosure and offer practical strategies that are tailored to the individual family situation. They can help caregivers decide what information to give to the adolescent and when, given their child’s age and development.

Supporting the caregiver in the disclosure process begins with the initial visits to clinic. The healthcare worker should:

- Build trust by getting to know the caregiver; find out what HIV means to him or her.
- Assess the caregiver’s psychosocial situation, ability to cope, answer questions, and establish their sources of support.
- Discuss the implications of disclosure with the caregiver and the family to help them consider in advance the reactions of the child, family members, friends, and teachers.
- Help the caregiver develop a plan of disclosure for the child. The plan will:
  - List any preparations they need to make before disclosure,

- Include what they will say, how and where they will disclose, and
- Include plans for ongoing support.
- Arrange to see the caregiver (and the adolescent) again, to review this process.
- If there is disagreement between family members about timing and process of disclosure, assess all family members' concerns, and discuss benefits and risks of disclosure, potential harm of long-term non-disclosure. Collaborate with caregivers to make a plan tailored to the needs of the entire family.
- Always respect and try to understand caregivers' reasons for fearing or resisting disclosure. Validation of caregivers' concerns can foster a partnership and prevent the development of an adversarial relationship between the members of the healthcare team and caregivers.

**Remember: If the caregiver is not ready to disclose, the process cannot be forced.** If the family or community situation is such that disclosure is not currently an option, the healthcare worker may assist the caregiver in determining which factors are within their control to change and which are not. The safety of the caregiver, infected child/adolescent, and other children in the household, as well as their need for continuing source of livelihood, are vitally important. If any of these issues will pose a potential risk, careful consideration should be given before disclosure discussions are initiated.

If the adolescent is not ready for the disclosure process, the caregiver and healthcare worker should try to determine the reasons:

- If the adolescent is not yet mature enough, the healthcare worker may suggest giving information to the adolescent a bit at a time, in language that the adolescent can accept, to allow him or her time to understand the information.
- If the adolescent appears to be emotionally unprepared, the healthcare worker may suggest that the caregiver let the adolescent know that both caregiver and healthcare worker are available to answer questions. A healthcare worker should always reassess the adolescent's readiness for disclosure over time.
- If the adolescent appears fearful of getting information, it may be that the client has overheard conversations and understands only a part of what has been heard. In this case, the healthcare worker should discuss with the caregiver how to encourage the young person to ask questions.

**An important task for the healthcare worker to assess is whether the caregiver is ready for disclosure.** The questions in

Table 7.3 can be used to assess the readiness of the caregiver, prepare for the process, and determine the level of support that he or she may require from the multidisciplinary care team:

**Table 7.3: Questions to assess caregiver disclosure support needs**

<b>1. Educating and preparing caregivers</b>
<ul style="list-style-type: none"><li>• What do they (the caregiver) think are the important points to communicate to the young person?</li><li>• How do other family members feel about disclosing? Do some family members feel that it is the right time for disclosure and others feel that it is not?</li><li>• What do they think will be the hardest part of the disclosure process?</li><li>• What do they think will be the hardest questions to answer?<ul style="list-style-type: none"><li>• Acknowledge that disclosure is difficult.</li><li>• Help caregivers anticipate the young person's questions and responses.</li></ul></li><li>• What are their feelings about their child's health (address any guilt or shame)?<ul style="list-style-type: none"><li>• Affirm the caregiver's commitment to disclosing to the child.</li><li>• Answer the caregiver's questions about HIV.</li><li>• Plan how the young person will receive support after disclosure.</li></ul></li></ul>
<b>2. Planning for disclosure</b>
<ul style="list-style-type: none"><li>• When and where will disclosure start?<ul style="list-style-type: none"><li>• Ideally when the adolescent is in a comfortable place, such as the home.</li><li>• With younger adolescents, encourage the caregiver to begin by playing with him or her, or conversing about the adolescent's day.</li></ul></li><li>• Who will lead the discussion and what is that person's relationship to the adolescent? Will there be other people involved, for example if the adolescent becomes angry and withdrawn or has questions that the caregiver may have trouble answering?</li><li>• How will they start the conversation?</li><li>• How will they provide support to the adolescent after disclosure?</li><li>• How might disclosure impact family members, friends, school, and community members?</li><li>• What support does the caregiver/family need?</li></ul>
<b>3. Planning ongoing follow up and support for caregiver</b>
<ul style="list-style-type: none"><li>• What support does the caregiver need to talk about the process and get answers to questions?</li><li>• Who does the caregiver have to talk with if he or she has questions?<ul style="list-style-type: none"><li>• Offer support to the caregiver to cope with their emotions and feelings after disclosure. Refer to a support group if possible.</li></ul></li><li>• When will the healthcare worker and caregiver meet again?<ul style="list-style-type: none"><li>• Plan for a follow-up counselling session with the adolescent and caregiver at the clinic.</li></ul></li></ul>
<b>4. Planning ongoing follow up and support for client</b>
<ul style="list-style-type: none"><li>• What support does the client need to talk about the process and get answers to questions?</li></ul>

- Who does the adolescent have to talk with if he or she has questions?
  - Offer support to the adolescent to cope with his or her emotions and feelings after disclosure. Refer to an ALHIV support group if possible.
  - Make sure the adolescent is given a chance to express their feelings — through talking, through role play, or through drawing, for example.
- When will the healthcare worker and client meet again?
  - Plan for a follow-up counselling session with the young person and caregiver at the clinic.
- What are the adolescent's next steps to support him or herself to live positively with HIV (for example, ALHIV support group)?
- To whom is the adolescent planning to disclose?
  - Plan for disclosure to others (other family members, teacher, or peers), as agreed appropriate with the caregiver.

Adapted from: The South to South Partnership for Comprehensive Family HIV Care and Treatment Program; International Center for AIDS Care and Treatment Programs; François Xavier Bagnoud, University of Medicine and Dentistry of New Jersey. 2010. "HIV Care & Treatment Training Series", Module 6: Disclosure Process for Children Ages 3 to 18 Living with HIV.



### **Trainer Instructions**

Slides 28-31

#### **Step 8:**

Explain that disclosure does not begin or end with a single conversation. Ongoing support for caregivers and clients with the disclosure process should be part of every subsequent clinic visit. Ask participants the following question and record key points on a flip chart.

- *How can healthcare workers provide ongoing support to adolescent clients and caregivers after the disclosure process has begun and the client knows about his or her HIV status?*

Again, refer participants to “Appendix 7A: Guidance for Developmentally Appropriate Disclosure”, and take 5–10 minutes to go over the 3<sup>rd</sup> and 4<sup>th</sup> columns. Ask one participant to read a sampling of questions from the first table (Younger adolescents), the 3<sup>rd</sup> column labeled:

- Possible questions the adolescent might have

After each question, ask the other participants to respond to the question (without referring to Appendix 7A), as they would if advising a caregiver.

The participant need not read all the questions/responses, just a few. Then ask another participant to read a sampling of questions from the 2<sup>nd</sup> age group (Older adolescents). Again ask other participants how they would recommend caregivers respond to this question.

**Step 9:** (optional) If he or she is willing and comfortable, ask the adolescent co-trainer to discuss experiences with disclosure including the need for post-disclosure support.



### Make These Points

- Disclosure is an ongoing process; follow up and additional support for the adolescent and caregivers is essential. As adolescents grow and develop, their understanding expands and they will have additional questions and new needs for information and support.
- Caregivers will need support both at the beginning of the disclosure process, as well as throughout the process.
- The role of the healthcare worker and caregiver is to continue talking to the adolescent, and to meet the ongoing needs of the adolescent as they arise.

## Ongoing Disclosure Support to Caregivers and Clients

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Disclosure does not begin or end with a single conversation. As adolescents grow and develop, they need to be able to continue to ask questions and discuss their feelings. Caregivers will also need ongoing support as the process proceeds over time.

Healthcare workers should remember to use a developmental approach to disclosure, incorporating some of the techniques in “Appendix 7A: Guidance for Developmentally Appropriate Disclosure”.

In general, 3 levels of ongoing support are needed for adolescents and caregivers coping with HIV-related disclosure:

- **Support by the healthcare worker:** The role of the healthcare worker and caregiver is to continue talking to the adolescent and to assess if the adolescent has further needs. New needs might include, for example, to understand more about the diagnosis, to have someone to talk to, or to make friends who are experiencing the same challenges that they are, or to try to reduce risk behaviours and live positively.
- **Support in the household:** As part of ongoing disclosure support, healthcare workers should specifically review the level of support within the household and who knows the adolescent’s diagnosis. It is also important to discuss when siblings will be told about the HIV status of an infected family member. Disclosure to siblings may provide an ongoing and positive source of support for adolescents living with HIV.

- **Support through peers:** Peer support for ALHIV and/or their caregivers can be very important. Peer support can be one-to-one, in small groups or in larger groups. Healthcare workers could approach caregivers who have successfully navigated the disclosure process and encourage them to start a peer group for other caregivers. Healthcare workers can also seek permission from one adolescent to pair him or her with another ALHIV who is going through or has just gone through similar life events.

The role of the healthcare worker is to facilitate an ongoing, truthful conversation about disclosure with the adolescent and caregiver over time. Once the disclosure process has begun (ideally well before the child reaches adolescence), at each visit, healthcare workers should ask the **client:**

- *Why do you think you take these medications? What do you know about HIV?*
- *How have you been feeling since you learned about your HIV status?*
- *Who else knows about your illness? Who else do you talk to about HIV?*
  - Refer the adolescent to a peer support group.
- *What other questions do you have?*
- *How are you doing with your medications?*

Once the disclosure process has begun (ideally well before the child reaches adolescence), at each visit, healthcare workers should ask the **caregiver:**

- *Have you noticed any changes in your child's behaviour after he or she learned about their HIV status?*
- *What kind of help, support, or information do you still need?*
- *What other questions do you have?*
- *What feelings or concerns do you have about the disclosure process with your child?*
- *Who does the adolescent have to talk with if he or she has questions?*
  - Remind caregiver to offer support to the adolescent to cope with their emotions and feelings after disclosure.
- *When will we meet again?*
  - Plan for a follow-up counselling session with the adolescent and caregiver at the clinic.



### **Trainer Instructions**

Slides 32-36

**Step 9:** Lead participants through Exercise 1, which gives an opportunity to practise how to assess readiness of caregivers for disclosure and help them prepare for the process.

**Exercise 1: Supporting Caregivers with the Disclosure Process: Start-stop role plays and large group discussion**

<b>Purpose</b>	<ul style="list-style-type: none"> <li>To give participants an opportunity to develop the knowledge, skills, and confidence to support caregivers and clients in the disclosure process</li> </ul>
<b>Duration</b>	45 minutes
<b>Advance Preparation</b>	<ul style="list-style-type: none"> <li>Read through and adapt the role plays as needed.</li> </ul>
<b>Introduction</b>	<p>Although the primary caregiver should preferably be the person to disclose to the child, caregivers will sometimes ask for help with the process. A healthcare worker can assist, first by preparing the caregiver and then, if asked, being present when the caregiver makes the disclosure. The healthcare worker’s role is to support the caregiver and facilitate the conversation between caregiver and child.</p>
<b>Activities</b>	<p><b>Start-Stop Role Play and Large Group Discussion</b></p> <ol style="list-style-type: none"> <li>Ask for 2–3 volunteers to role play a “healthcare worker”, “client”, and “caregiver,” depending on the case study.</li> <li>Refer the actors to the first case study (below) and to “Appendix 7A: Guidance for Developmentally Appropriate Disclosure” in their Participant Manuals.</li> <li>Give actors a few minutes to prepare for their role and then ask the group to get started with the role play.</li> <li>The trainer should stop (“freeze”) the actors from time to time so that the large group can discuss what is going on.</li> <li>During the first “freeze,” ask the large group 1 or 2 of the following questions to facilitate discussion: <ul style="list-style-type: none"> <li><i>What types of questions are adolescents in the case studies likely to ask about their illness? What are some possible responses? (Refer to “Appendix 7A: Guidance for Developmentally Appropriate Disclosure”)</i></li> <li><i>What can the healthcare worker do to help the caregiver prepare for the disclosure process?</i></li> <li><i>How can the healthcare worker assess the caregiver’s readiness or knowledge about disclosure?</i></li> <li><i>What age-specific activities, if any, can the healthcare worker introduce in the session?</i></li> </ul> </li> <li>Ask the actors to continue their role play, incorporating the suggestions from the large group.</li> <li>After the second “freeze,” ask the actors to role play again, pretending as if one month has passed since the original discussion.</li> <li>Repeat this exercise using the remaining 2 case studies</li> </ol>

	<p>so that different participants have an opportunity to practise each role.</p> <p>9. (optional) Encourage participation from the adolescent co-trainer, who can act as the adolescent client in the role plays. Ask the following question to encourage discussion:</p> <ul style="list-style-type: none"> <li>• <i>How did you feel during this exercise? Were you satisfied with how the healthcare worker tried to offer you support?</i></li> <li>• <i>What did he or she do well?</i></li> <li>• <i>What could he or she do differently?</i></li> </ul>
<b>Debriefing</b>	<ul style="list-style-type: none"> <li>• The disclosure process can present with many complex personal and family issues. Healthcare workers may find themselves in a position to support family in dealing with these many issues. When faced with a new scenario, it can be helpful to consult with other members of the multidisciplinary care team to get their suggestions on how to best deal with the situation.</li> <li>• Healthcare workers may be asked to act as intermediaries, that is, guiding caregivers rather than doing the disclosure themselves with adolescent clients. Therefore, healthcare workers need to take into account the needs, wishes and views of caregivers, and allow them to feel a sense of control over the process.</li> </ul>

**Exercise 1: Supporting Caregivers with the Disclosure Process: Start-stop role plays and large group discussion**

**Case Study 1:**

A mother named Ethel has been caring for her HIV-infected 10-year-old son, Tylor. Tylor keeps asking you why he has to take these pills and wants to know when he will finish taking them. When you ask the mother what Tylor knows about his health, she becomes quiet. How would you proceed with Ethel?

**Key points for trainers: Ethel and Tylor**

- The healthcare worker should talk with Ethel on a one-to-one basis (Tylor should not be in the room) to provide her with an opportunity to respond to your question about what Tylor knows about his health. Give Ethel time to compose her thoughts, allow the silence in the room to remind her that you are patiently waiting for a response.
- Use listening and learning skills to encourage Ethel to talk. We can probably assume by her lack of response that she has not disclosed to Tylor. But there must be some reason for this, encourage her to discuss these reasons.
- Then decide how to tackle the barriers to disclosure one-by-one. It may take months to tackle all of the barriers.
- Then decide how to respond to Tylor’s immediate questions. Remind

Ethel that Tylor's questions indicate that he needs more information about his diagnosis. As he is 10 this is about the time to think about full disclosure.

- Come up with a disclosure plan. Target an approximate time when Ethel thinks she will be ready to start the disclosure process with Tylor (next week? 6 months from now? 9 months from now?). Discuss how she thinks she would like to disclose and then ask what support she and Tylor will need before, during and after the process. Document the plan in Tylor's record, but let Ethel know that the plan can be changed, if it needs to be.
- Refer to the plan at the next visit and ask Ethel for an update.

### **Case Study 2:**

Amukusana is 11 years old. She has lived with her grandmother since her mother died three years ago. Amukusana and her grandmother have been visiting the clinic since Amukusana started to become symptomatic. The doctor wants her to start ART soon. Grandmother is having problems giving Amukusana her CTX. You believe that Amukusana would cooperate better if she understood more about the medication and why she needs it, especially since ART is now about to become part of their lives. Grandmother thinks Amukusana is too young to know her status and insists she does not need to know. How do you proceed?

#### **Key points for trainers: Grandmother and Amukusana**

- First you need to address Grandmother's point about Amukusana being too young to know her HIV status. Discuss the advantages of knowing and reassure her that studies have shown that adolescents who know their HIV status have higher self-esteem than young people who are unaware of their status.
- Discuss the process of disclosure, reassuring Grandmother that we will proceed one step at a time, letting Amukusana know just a bit more during each conversation, but only what is appropriate for her at her current developmental stage.
- Connect Grandmother with other caregivers who have disclosed — particularly other caregivers who had the same reservation as does Grandmother.
- You can offer to develop a disclosure plan at today's visit, or more likely, wait until the next visit to offer to discuss a concrete disclosure plan. Give Grandmother time to think about what you've said and to talk to another caregiver who has been through the disclosure process.

### **Case Study 3:**

Gabriel is a 12-year-old boy living with HIV and taking ART. He lives with his mother, maternal uncle, and 5 older half-siblings and cousins. Each

time Gabriel comes to the clinic he gets very agitated when he gets blood drawn, and recently has been asking “*Why do I need to take medicines?*” and “*Why am I always coming here?*” Today, Gabriel seems very upset that he has to come to the doctor instead of playing with his cousins. When you ask, his mother has not told Gabriel anything about his HIV status or the reasons she has to come to the clinic so much. She asks your advice about what to do and asks for your help disclosing to Gabriel. How do you proceed?

#### **Key points for trainers: Gabriel**

- It sounds like Mother is ready to discuss a disclosure plan and Gabriel is ready to hear his diagnosis. Discuss the advantages of disclosure.
- You might want to first discuss how Mother should respond to Gabriel’s questions. You can role play with her if it helps. Inform Mother that Gabriel’s questions indicate that he needs more information about his diagnosis. Many ALHIV his age already know their diagnosis.
- Start to develop a disclosure plan. When discussing the pre-disclosure activities, use listening and learning skills to encourage Mother to brainstorm all barriers and any complexities related to disclosure. For example, does Uncle know Gabriel’s HIV status? How about the half-siblings and cousins? If not, should they know? If so, when and who will tell them?
- Target an approximate time when Mother thinks she will be ready to start the disclosure process with Gabriel (next week? next month?). Discuss how she thinks she would like to disclose and then ask what support she and Gabriel will need before, during and after the process. Note the plan in Gabriel’s record, but let Mother know that the plan can be changed, if it needs to be.
- Refer to the plan at the next visit and ask Mother for an update.



#### **Trainer Instructions**

**Step 10:** Allow 5 minutes for questions and answers on this session.

## Session 7.3

# Disclosure Counselling and Support for Adolescents Who Know Their Status



**Total Session Time:** 90 minutes (1 hour, 30 minutes)



### Trainer Instructions

Slides 37-38

- Step 1:** Begin by reviewing the session objective listed below.
- Step 2:** Ask participants if there are any questions before moving on.

### Session Objective

**After completing this session, participants will be able to:**

- Provide counselling and support to adolescents on disclosing their HIV status to others.



### Trainer Instructions

Slides 39-40

- Step 3:** Explain that healthcare workers can help adolescents overcome their fear of disclosure and help them deal with important issues, such as self-stigma. Explain that making decisions about disclosure of HIV status is an important step for ALHIV who may have cause to fear rejection and violence from family, friends, and partners. Some adolescents may even have to confront additional stigma, due to their sexual orientation or gender identity, or may fear disclosing because they are embarrassed or ashamed about past choices.

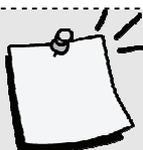
Write the word “**ADVANTAGES**” on a piece of flip chart paper and “**DISADVANTAGES**” on another piece. Ask respondents to brainstorm about the potential advantages and disadvantages of disclosure for ALHIV, and record the discussion on the flip chart pages.

Debrief by briefly discussing what happens in your community in relation to disclosure. Emphasize that helping a client think about the advantages and disadvantages of disclosure is an important part of supporting the disclosure process.

- Step 4:** (optional) If he or she is willing and comfortable, ask the

adolescent co-trainer to continue with their description about disclosure in their life.

- *What were your fears about disclosure?*
- *What were the advantages/disadvantages of disclosing?*
- *Who supported you with the disclosure process?*
- *How did healthcare workers assist you, or could have better assisted you, with this process (if applicable)?*



### **Make These Points**

- ALHIV can feel very isolated. A healthcare worker can help adolescents understand that one of the advantages of disclosure is that you will have friends who know your diagnosis and can support you.
- Because of their special status (no longer a child, not yet an adult), adolescents need support with the disclosure process from the entire multidisciplinary care team.
- Adolescents should always make their own decisions about disclosure.
- Healthcare workers can support adolescents to decide whom to disclose to, decide when and where to disclose, weigh the advantages and disadvantages of disclosure, and assist them to anticipate likely responses.

## **Providing Disclosure Support to ALHIV**

Healthcare workers can work with ALHIV to help them understand why disclosure is important and to whom they should disclose, based on the advantages and disadvantages. Healthcare workers can also help ALHIV to prepare for disclosure and provide follow-up support.

### **Advantages of disclosure may include:**

- Avoid the burden of secrecy and feeling of hiding
- Avoid anxiety about accidental or unwanted disclosure
- Access to emotional and practical support from peers or family members, including the freedom to talk about symptoms and concerns
- Easier access to health care
- Enhanced adherence to care and medication
- Ability to discuss safer sex and family planning choices with one's partner(s)
- Ability to refer partner for HIV counselling and testing, and to care and treatment, if needed
- Freedom to ask a friend or relative to be a treatment buddy
- Access to peer support groups and community organisations
- Serve as a role model for other people on disclosure

## Disadvantages of disclosure may include:

- Blame by partner or family for “bringing HIV into the household”
- Distancing, fear, rejection or abandonment by partner, family or friends/classmates
- Discrimination at school
- Discrimination in the community
- Discrimination at work, including possible loss of job
- Assumptions made about sexuality, promiscuity or lifestyle choices
- Rejection in the community
- Reluctance on the part of partner to enter into intimate relationships or have children
- Physical violence
- Self-stigma
- Loss of economic/subsistence support from family members or partners



### Trainer Instructions

Slides 41-46

**Step 5:** Explain that by helping ALHIV to “break the silence” — that is, by helping them to disclose their HIV status — healthcare workers can help adolescents overcome their fear of disclosure and help them deal with issues, such as potential blame and stigma.

Ask participants to brainstorm about the role of the healthcare workers in disclosure counselling and support for ALHIV. Ask the following question to facilitate discussion:

- *What are some different ways healthcare workers can help support adolescents when they are considering disclosing their HIV status to others?*
- *What are some of the main points or considerations in disclosure counselling with ALHIV?*

Fill in using the content below.

**Step 6:** (optional) If he or she is willing and comfortable, ask the adolescent co-trainer to describe who supported or helped him or her during the disclosure process to others (family members, friends, boy/girlfriends, etc.).



### Make These Points

- Because disclosure is a process, it is important that healthcare workers

continue to check in with clients about the progress clients are making and the challenges they are encountering disclosing their HIV status to others. This should NOT include putting pressure on clients to disclose, but should rather focus on supporting clients to work through issues related to disclosure, and helping them make a plan if they have decided they want to disclose their status to others.

- Healthcare workers can counsel and help adolescents practise disclosure through role plays with clients, including providing practical suggestions about how they will start the conversation.
- Adolescents may find it helpful to meet each other for mutual support and discuss personal issues, thoughts, and struggles related to the disclosure process.

## **Helping ALHIV with the Disclosure Process**

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Disclosure counselling:

- Should not include pressure to disclose.
- Is a confidential conversation that assists clients to work through the issues related to telling others about their HIV status.
- Is important to reduce stigma, enhance adherence to care and treatment, and reduce the spread of HIV.
- Is intended to promote informed decisions about whether or not to disclose HIV status and, if so, to whom.
- Assists and supports clients who have decided to disclose their status.
- Enhances coping strategies following disclosure.
- Uses a tailored and developmental counselling approach, as each adolescent is unique.
- Is an ongoing process that requires preparation, practise and follow-up support.

Adolescents should make their own decisions about disclosure, but healthcare workers can assist ALHIV in the disclosure process by:

- Using good communication and counselling skills (for example, the 7 Listening and Learning Skills from Module 4).
- Talking about the client's fears and feelings around disclosure.
- Discussing the advantages and disadvantages of disclosure specific to the person's life.
- Supporting clients to make their own decisions about disclosure.
- Helping clients decide whom to disclose to, when and where.
- Helping the adolescent identify barriers to and fears about disclosure.
- Exploring possible options to overcome barriers.
- Providing accurate and detailed information in response to questions.
- Assisting the adolescent to anticipate likely responses, including possible negative reactions to disclosure.
- Talking about current and past sexual partners who need to be notified of their risk of HIV.
- Offering reassurance and emotional support.

- Identifying sources of support and referring clients to peer support groups.
- Encouraging the client to take the time needed to think things through.
- Practising disclosure through role plays with clients, including practical suggestions about how they will start the conversation. For example, you can suggest the following “conversation starters” to clients who are confused about what to say to family or friends:
  - *“I wanted to talk to you about something because I know you can help and support me.”*
  - *“I went to the clinic today for a check-up and they talked to me about how it is important for everyone to get an HIV test because you cannot tell if someone has it by looking at them.”*
  - *“I want to talk with you about something very important. I am talking to you about it because I love you and I trust you.”*
  - *“I need to talk to you about something that is very difficult for me to discuss.”*
- Providing ongoing follow up and support through the disclosure process

### **Peer support and disclosure**

Peer support can be an excellent resource for adolescent clients who are deciding about disclosure:

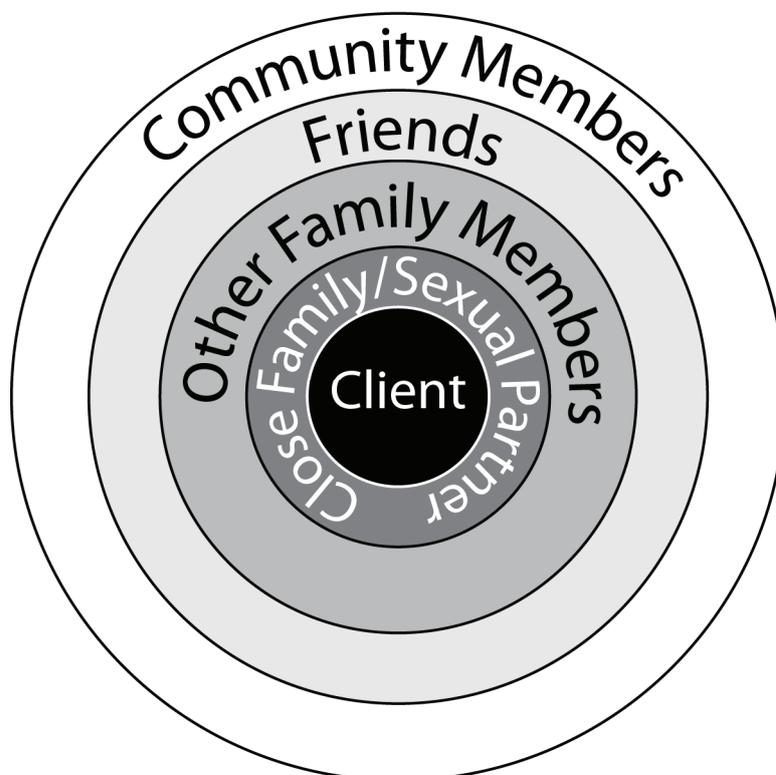
- **Peer Educators and peer support groups:** Adolescents may find it helpful to meet each other for mutual support.
- **Groups for caregivers of ALHIV:** Family members of ALHIV may also benefit from talking with other families or with a healthcare worker in a support group setting.

### **Deciding about disclosure**

- A good way to understand disclosure and help adolescents decide who they will disclose to is by creating “disclosure circles” with your client, see Figure 7.1: Disclosure circle.
- The centre of the circle is the adolescent (self).
- The next circle out is a person or people the adolescent is very close to, such as a mother, siblings or partner (give the adolescent a piece of paper so that he or she can write the names of the people at this and the next layers of his or her own disclosure circle) .
- The next circle includes larger groups of people that the person is not as close to, such as people at work or others in the community.
- There can be many layers to the circles of disclosure.
- Each layer of disclosure represents a process in itself — preparing for disclosure, the disclosure process, and ongoing conversations after disclosure. Remember that the conversation does not end after disclosure. There will probably be ongoing discussions between the client and the person she or he has disclosed to over time.
- The goal is NOT that all people will eventually disclose to all of the people in the circles. Instead, the circles provide a way to discuss the

disclosure process, consider the risks and benefits of disclosing to different people, and help prioritise disclosure activities.

**Figure 7.1: Disclosure circle**



Source: Colton, T., Costa, C., Twyman, P., Westra, L., and Abrams, E. 2009. *Comprehensive Peer Educator Training Curriculum, Trainer Manual, Version 1.0.*, International Center for AIDS Care and Treatment Programs.



**Trainer Instructions**

Slides 47-52

**Step 7:**

Lead participants through Exercise 2, which gives an opportunity to discuss how to support ALHIV plan and prepare them for the disclosure process and how to apply use strategies, such as disclosure circles, in the counselling process.

<b>Exercise 2: Supporting ALHIV with the Disclosure Process: Role plays and large group discussion</b>	
<b>Purpose</b>	<ul style="list-style-type: none"> <li>To provide participants with an opportunity to discuss strategies for providing ALHIV assistance with the disclosure process</li> </ul>
<b>Duration</b>	50 minutes
<b>Advance Preparation</b>	<ul style="list-style-type: none"> <li>Read through and adapt the role plays as needed.</li> </ul>
<b>Introduction</b>	<p>Helping adolescent clients to understand their illness and negotiate the process of disclosure is an essential component of good health care. Healthcare workers can counsel ALHIV about the implications of disclosure and help them prepare for and anticipate other people's reactions.</p>
<b>Activities</b>	<p><b>Role Play and Large Group Discussion</b></p> <ol style="list-style-type: none"> <li>1. Ask participants to review the case studies in their Participant Manuals.</li> <li>2. Ask 2 participants to volunteer to be the "healthcare worker" and "client."</li> <li>3. Ask participants to role play the first case study in front of the large group, incorporating into the dialogue the material discussed in this module. As part of the role play, the "healthcare worker" should help the "client" create a "disclosure circle" during the counselling session.</li> <li>4. If there is sufficient time, continue to role play the remaining 3 case studies. If not, discuss potential responses to the situations in a large group and answer the following questions: <ul style="list-style-type: none"> <li>• <i>How would you counsel and support the client in the disclosure process? How would you help them to prepare for disclosure?</i></li> <li>• <i>What are some of the client's potential questions/fears/concerns related to disclosure and how would you address them?</i></li> <li>• <i>What age-appropriate communication techniques/approaches would you use to build trust and rapport?</i></li> </ul> </li> <li>5. (optional) Encourage participation from the adolescent co-trainer, who can act as the adolescent client in the role plays. Ask the following question to encourage discussion: <ul style="list-style-type: none"> <li>• <i>What else could the healthcare worker do to communicate effectively with the adolescent client and support him or her in the disclosure process?</i></li> </ul> </li> </ol>
<b>Debriefing</b>	<ul style="list-style-type: none"> <li>The plan for disclosure is unique for everyone. Healthcare workers should remember that adolescents</li> </ul>

	<p>are a diverse group and take these differences into account (for example, age, developmental status, personal and family experience of stigma and discrimination) when counselling clients about disclosure.</p> <ul style="list-style-type: none"> <li>• A good way for healthcare workers to help ALHIV understand disclosure and help them decide who they will disclose to is by creating “<b>disclosure circles.</b>”</li> <li>• The role of the healthcare worker is to advise and support the disclosure process. It is the adolescent who will make the final decision on who to disclose to, when and how.</li> </ul>
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## Exercise 2: Supporting ALHIV with the Disclosure Process: Role plays and large group discussion

### Case Study 1:

Chabala is 15 years old and found out that he is HIV-infected at a VCT clinic 2 months ago. He returned for a second visit to the ART clinic, and says that he has not yet told anyone about his HIV status because he is too ashamed and scared to tell his family. How would you help Chabala?

### Key points for trainers: Chabala

- Let Chabala know that it is very normal to not want to tell a sole about your HIV status if very recently diagnosed. Start the conversation by first reminding him that this conversation is confidential (as a way to build trust and to lay the foundation for the counselling session). Then ask: “*Is there anyone to whom you would **like** to disclose?*” This might be a good time to draw a disclosure circle, identifying the names of the people at the first three of the four levels:
  - Close family/sexual partner
  - Other family members
  - Friends
  - Community members
- Suggest that he prioritise disclosure to the people that he named in the circle entitled “close family/sexual partner”.
- Keep his response in mind as you go through a summary of some of the advantages and disadvantages of disclosure. If he does not have a sexual partner at the moment, then there is no rush to disclose just yet; although he might really need the support that disclosure to a close friend or parent could bring.
- Ask him: “*What concerns do you have about disclosing your HIV status?*” Work with him on his fears and barriers. Some barriers are easier than others. If he has HIV because he was sexually molested, then disclosure will involve a myriad of personal, family and emotional issues, and he may require extensive support and time.
- At this point, because Chabala was recently diagnosed, focus the disclosure discussion on the first level in the disclosure circle “close

family/sexual partner”. Maybe he can aim to tell one person before his next appointment (the person who he thinks can support him). If he has a sexual partner, this person should also be prioritised for disclosure, if not initially, then soon after.

- Work with Chabala to develop a plan: when is he going to tell this person (let’s assume it is his best friend, who is also a male)? Where will they be when he tells him? If he would find it helpful, offer to role play the actual disclosure scenario.
- Ask what Chabala thinks this friend’s response is likely to be. Ask what questions he is likely to have. Role play with him how to respond to his reaction and questions.
- Offer reassurance and emotional support.
- Use this opportunity to find out if Chabala is sexually active, if so, discuss the importance of ensuring he uses condoms each and every time he has sex and give him condoms (if available).
- Make an appointment for a follow-up visit. Let him know that you will be available between appointments should have any questions.
- Be certain to refer Chabala to a support group. Clients particularly need peer support early after diagnosis.

### **Case Study 2:**

Lelemba is a 16-year-old girl who was perinatally infected with HIV. Lelemba mentions that she really wants to disclose her status to one of her male friends at school. Lelemba likes this boy very much and she knows that he likes her, but she is nervous about her friend’s reaction. They have been arguing recently because Lelemba has been avoiding him. She asks your opinion about what to do. How do you proceed?

### **Key points for trainers: Lelemba**

- You may want to start by reminding Lelemba that this session is confidential, as this helps build trust and lays foundation for any counselling session
- Although Lelemba wants to disclose to this boy, her motivation — and their relationship — are somewhat unclear. So, consider starting the conversation by finding out why she wants to disclose: *“Lelemba, why do you think you would like to tell this boy that you have HIV?”* During the discussion, ask questions to encourage her to talk a bit more about the relationship and whether or not the relationship is sexual.
- This might be a good time to draw a disclosure circle, identifying some of the names of the people at the first three (of four) levels:
  - Close family/sexual partner
  - Other family members
  - Friends
  - Community members
- The placement of this boy in the disclosure circle might help Lelemba

decide if he should be priority for disclosure. But if this boy ends up being named at level 3, then there may not be a good argument for disclosing to him right now, and should be reconsidered in the future.

- If Lelemba is **not** having sex with this boy and there is no immediate plan for the relationship to progress to being a physical one, encourage her to think through the advantages and disadvantages of disclosure and take her time before she takes this step. Ensure that her reasons for disclosure are appropriate (not manipulative) and that she is reasonably assured that he will keep this information confidential.
- If Lelemba has had sex with this boy or is planning to have sex with him in the near future, praise her decision to disclose and support it.
- Using your listening and learning skills (Module 4), talk about her fears and feelings around disclosure.
- Ask about barriers/anticipated negative reactions, “You’re obviously hesitant about telling him that you have HIV, why do you think that is?” Work through these barriers with her.
- Work with Lelemba to develop a plan: when is she going to tell him? Where will they when she tells him? If she would find it helpful, offer to role play the actual disclosure scenario.
- Ask what the boy’s response is likely to be. Ask what questions he is likely to have. Role play with her how to respond to the boy’s reaction and questions.
- Offer reassurance and emotional support.
- Use this opportunity to discuss the importance of dual protection: using condoms each and every time she has sex as well as another form of family planning (such as the pill). Provide her with condoms (if available) and show her how to use them. Also discuss other family planning options, such as the pill (dual protection).
- Make an appointment or a follow-up visit. Let her know that she can come alone or with her boyfriend. Let her know that you will be available between now and the appointment in case she would like to come in with this boy for additional counselling, answers to questions she was unable to answer, or HIV testing.
- If you have another client who has been through a similar conversation, consider pairing them for peer support.

### **Case Study 3:**

Josephine is a 14-year-old female orphan with HIV that lives with her maternal aunt and uncle. Josephine just started a new school and is afraid that she will be thought of as different from the other kids if anyone finds out she is living with HIV. She has not disclosed her status to anyone at school. How would you proceed with Josephine?

### **Key points for trainers: Josephine**

- Let Josephine know that it is very normal to not want to tell friends at

school about your HIV status, for one thing she has just started at that school, so she does not yet know anyone well.

- Remind Josephine that this discussion (between yourself and Josephine) is confidential, as this helps build trust and lays foundation for the counselling session.
- Ask her: *“Who know that you have HIV?” “Are you getting the emotional support you need from these people?”*
- This might be a good time to draw a disclosure circle, identifying the names of the people at the first three of the four levels:
  - Close family/sexual partner
  - Other family members
  - Friends
  - Community members
- Ask her: *“How do you get along with your close family members?” “How do you get along with your aunt and uncle? How about your cousins? “Do you have a partner?”*
- Ask: *“Who, of the people listed in the first level “close family/sexual partner” knows you have HIV?”* If everyone, and she has already stated that she gets the emotional support she needs, then let her know that for the time being, she really does not need to disclose to anyone else. She will want to reconsider this decision as she makes close friends at school, perhaps a (new) boyfriend. For the time being, she should feel free to keep her HIV status a secret from the others at school.
- If, though, she feels she is not getting the emotional support she needs — for example, if her aunt and uncle do not provide her with the emotional support she needs — then she might want to consider disclosing to others in the “close family/sexual partner” level or the “Other family members” level (cousin, another aunt, etc).
- If she feels inadequately supported, then ensure she is referred to a peer support group and think about referring her for additional counselling, including family counselling.
- If she has a partner, ask her if she has discussed her HIV status with her partner. Is he a potential source of support? Also, take a moment to discuss safer sex and provide her with condoms.
- Make an appointment to meet again. If Josephine is not getting support from anyone in her “close family/sexual partner” level, then make sure the follow-up appointment is relatively soon (if possible, within the week) so that you can track progress and provide additional support.

#### **Case Study 4:**

An 18-year-old named Isaac tested positive for HIV about 2 years ago. He takes good care of himself and feels fine. He got tested because his girlfriend at that time found out she was HIV-infected. He has since changed girlfriends and has not told his new girlfriend about his HIV status. He comes to the clinic for his regular appointment, but wants to talk

with you about how to tell his girlfriend that he is living with HIV. How would you help Isaac prepare for the disclosure process to his girlfriend?

### Key points for trainers: Isaac

- Isaac knows that he wants to disclose to his girlfriend, so there is no need to discuss advantages and disadvantages, instead praise his decision and let him know that you can support him.
- Remind Isaac that your discussion is confidential. Then ask about barriers/anticipated negative reactions, *“You seem hesitant about telling your girlfriend that you have HIV, can you tell me why?”* Work through the barriers with him.
- Work with Isaac to develop a plan: when is he going to tell her? Where will they be when he tells her? If he would find it helpful, offer to role play the actual disclosure scenario.
- Ask what her response is likely to be. Ask what questions she is likely to have. Role play with him how to respond to her reaction and questions.
- Offer reassurance and emotional support.
- Use this opportunity to discuss the importance of ensuring he uses condoms each and every time he has sex. Give him condoms, ensure he knows how to use them. Also ask him about whether or not his girlfriend is using another form of family planning (dual protection).
- Recommend that he strongly suggest to his girlfriend that she come in for HIV testing. Provide referrals for HIV testing.
- Let him know that you will be available in case he would like to come in with his girlfriend for additional counselling or answers to questions he was unable to answer.
- If you have another client who has been through a similar conversation with his girlfriend, consider pairing them for peer support.
- Make an appointment for a follow-up visit.

Note: Although the directions for this exercise suggested using the disclosure circle, the disclosure circle provides support with deciding to whom to disclose, whereas Isaac came in requesting support to disclose to a specific person (who happens to be at the first level in the disclosure circle “close family/sexual partner”, so the healthcare worker will naturally agree with his decision). So, the disclosure circle may not be appropriate for this counselling session, but it might be appropriate in the future if he feels the need to widen his support network.



### Trainer Instructions

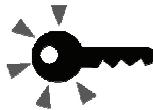
**Step 8:** Allow 5 minutes for questions and answers on this session.



### **Trainer Instructions**

Slides 53-54

- Step 9:** Ask participants what they think the key points of the module are. What information will they take away from this module?
- Step 10:** Summarise the key points of the module using participant feedback and the content below.
- Step 11:** Ask if there are any questions or clarifications.



### **Module 7: Key Points**

- Disclosure is an ongoing process, not a one-time event. Most adolescents and their caregivers need support with planning disclosure, the actual disclosure conversation and post-disclosure follow up.
- Disclosure can help a person access prevention, care, treatment and support; improve adherence; help reduce stigma and discrimination by bringing HIV out into the open; and slow the spread of HIV by helping people protect themselves and their partners.
- Healthcare workers can work with caregivers and adolescents to help them to understand why disclosure is important, help them overcome their barriers to disclosure, assist them with preparing for disclosure, assist them with the disclosure process, and provide follow-up support.

## Appendix 7A: Guidance for Developmentally Appropriate Disclosure

Age group characteristics	Disclosure considerations and guidance	Possible questions the adolescent might have	Possible responses to questions or ways of explaining things to the adolescent
<b>Younger adolescents (approx 10–13 years old)</b>			
<ul style="list-style-type: none"> <li>Beginning to understand cause and effect, but still struggles with abstract concepts</li> <li>Growing vocabulary, but struggles to express ideas and feelings in words</li> <li>Enjoys activities that give a chance to control, organise and order things</li> <li>May regress and want help from adults if feeling insecure or unsure</li> </ul>	<ul style="list-style-type: none"> <li>Be truthful</li> <li>Ideally, the disclosure process will have already started by this age</li> <li>Give more detailed information, with concrete examples.</li> <li>If a child asks for more information (for example, “<i>What’s the germ called?</i>” or “<i>How did the germ get in my body?</i>”) give short, clear answers.</li> <li>Help the child deal with possible stigma.</li> <li>Reassure the child that he or she can ask further questions or share any concerns now or later.</li> </ul>	<ul style="list-style-type: none"> <li><i>Why do I have to go to the clinic?</i></li> <li><i>Why am I sick?</i></li> <li><i>Why do I have to go to the clinic so much?</i></li> <li><i>Why do I have to take medicine?</i></li> <li><i>Am I going to die?</i></li> <li><i>How did I get HIV?</i></li> <li><i>Who knows that I have HIV?</i></li> <li><i>Do I have to tell people I have HIV?</i></li> <li><i>What will happen if people know I have HIV?</i></li> </ul>	<ul style="list-style-type: none"> <li><i>Going to the clinic will help you stay well.</i></li> <li><i>You have a virus in your blood called HIV. It attacks the germ fighters in your body. This is why you get sick sometimes.</i></li> <li><i>You and I (if mother or caregiver is also HIV-infected) both have HIV in our bodies.</i></li> <li><i>You have to take medicine so the germ fighters can work and you won’t get sick so much.</i></li> <li><i>You (and I, if appropriate) take medicine to keep us strong.</i></li> <li><i>The medicines that we have to treat this virus are very good. If you take your medicine the right way, every day and never miss a dose, you can stay healthy for a very long time.</i></li> <li><i>HIV is nothing to be ashamed of, but it is something private. You don’t have to tell other people if you don’t want to.</i></li> <li><i>You can always talk to me about it at any time.</i></li> <li><i>Maybe we should keep this in the family for now?</i></li> </ul>

Age group characteristics	Disclosure considerations and guidance	Possible questions the adolescent might have	Possible responses to questions or ways of explaining things to the adolescent
<b>Older adolescents (approx 14–19 years old)</b>			
<ul style="list-style-type: none"> <li>• Early adolescents beginning to be able to think in more abstract terms</li> <li>• Want solid, well-thought-out explanations</li> <li>• Body changes can create feelings of insecurity</li> <li>• Forming a sense of identity — peer approval and social acceptance very important</li> </ul>	<ul style="list-style-type: none"> <li>• Ideally, the adolescent will have been fully disclosed to by this age.</li> <li>• Accurate and more detailed information can be given in response to questions.</li> <li>• Realistic information about health status should be given, and all questions should be answered.</li> <li>• Be sure to ask about and discuss the adolescent's feelings and fears about HIV.</li> <li>• Ask questions about their understanding and address misperceptions, for example, "What have you heard about HIV?"</li> <li>• Ways to live meaningfully with HIV, including having relationships, are a common concern. Issues like risk reduction and living positively with HIV should be discussed.</li> <li>• Being assured that their status and what they say is</li> </ul>	<ul style="list-style-type: none"> <li>• What is HIV?</li> <li>• Why do I have it?</li> <li>• Can I give HIV to my (girl/boy) friends? How?</li> <li>• Why do I have to go to the clinic so often?</li> <li>• What are the healthcare workers looking at in my blood?</li> <li>• What if I want to get married and have children? Is that possible for people living with HIV?</li> <li>• Who should I tell that I have HIV?</li> <li>• Why are people mean to people with HIV?</li> </ul>	<ul style="list-style-type: none"> <li>• You have the HIV virus. A virus is something that gets into your blood and can make you sick. Having HIV does not mean that you are sick all the time.</li> <li>• Healthcare workers look at your blood to see how many healthy cells, called CD4 cells, are in it. The higher your CD4 count, the better.</li> <li>• You can control the virus by taking your medication every day, at the same time and never missing a dose. But there is no way you can get rid of HIV completely.</li> <li>• If you stop taking your medicine, the virus will get stronger and damage all of your healthy CD4 cells. If that happens you can get sick.</li> <li>• Knowing that you have HIV gives you a special responsibility to take extra good care of yourself and not pass HIV to other people.</li> <li>• People with HIV can and do live long lives, have relationships and get married.</li> <li>• If you have sex, it is important for you and your partner that you use condoms. Taking your ARVs the right way, every day also lowers the amount of virus in your body and makes it less likely that you will pass HIV to your partner during sex.</li> <li>• You can have a baby in the future, but there</li> </ul>

Age group characteristics	Disclosure considerations and guidance	Possible questions the adolescent might have	Possible responses to questions or ways of explaining things to the adolescent
	<p>confidential is very important.</p> <ul style="list-style-type: none"> <li>• Normal adolescent striving for independence may complicate the response to disclosure (for example, result in a decline in adherence).</li> <li>• Issues of disclosure to others should be discussed, but the adolescent should make his or her own decisions on this matter.</li> <li>• Assurance of support and willingness to help should be given without seeming intrusive.</li> </ul>		<p>are risks of passing HIV to your partner or to the baby. There are many things you could do to lower the chances that your baby would get HIV. Taking your ARVs the right way, every day will help lower the chance of passing HIV. We can talk more about this whenever you like.</p>

Adapted from: The South to South Partnership for Comprehensive Family HIV Care and Treatment Program; International Center for AIDS Care and Treatment Programs; François Xavier Bagnoud, University of Medicine and Dentistry of New Jersey. 2010. "HIV Care & Treatment Training Series", Module 6: Disclosure Process for Children Ages 3 to 18 Living with HIV.

## References and Resources

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<sup>1</sup> Adherence Networking Group. 2006. Kids Count: Guide for Trainers, Children's ART Adherence Resource Pack.

<sup>2</sup> The South to South Partnership for Comprehensive Family HIV Care and Treatment Program; International Center for AIDS Care and Treatment Programs; François Xavier Bagnoud, University of Medicine and Dentistry of New Jersey. 2010. "HIV Care & Treatment Training Series", Module 6: Disclosure Process for Children Ages 3 to 18 Living with HIV.

<sup>3</sup> The South to South Partnership for Comprehensive Family HIV Care and Treatment Program; International Center for AIDS Care and Treatment Programs; François Xavier Bagnoud, University of Medicine and Dentistry of New Jersey. 2010. "HIV Care & Treatment Training Series", Module 6: Disclosure Process for Children Ages 3 to 18 Living with HIV. Pages 6-19.



# Module 8 Supporting Adolescents' Retention in, and Adherence to, HIV Care and Treatment



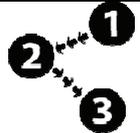
**Total Module Time:** 240 minutes (4 hours)

## Learning Objectives

**After completing this module, participants will be able to:**

- Define retention in, and adherence to, HIV care and treatment.
- Identify common barriers to retention in care and adherence to treatment among adolescent clients.
- Discuss ways that healthcare workers and health facilities can support adolescents' retention in and adherence to care.
- Conduct adherence preparation sessions with adolescents who are starting ART, and their caregivers.
- Assess adolescent clients' (and caregivers) adherence.
- Provide ongoing, age-appropriate support to improve adolescent clients' (and caregivers) adherence.

## Methodologies



- Interactive trainer presentation
- Large group discussion
- Brainstorming
- Small group work
- Case studies
- Role play

## Materials Needed



- Slide set for Module 8
- Flip chart and markers
- Tape or Bostik
- Any adherence support tools that are available to adolescents, such as pill boxes, medicine calendars or diaries, etc.
- Participants should have their participant manuals. The Participant Manual contains background technical content and information for the exercises.



### References and Resources



- Republic Of Zambia, Ministry Of Health. 2010. *Adult and Adolescent Antiretroviral Therapy Protocols 2010*.
- Colton, T., Costa, C., Twyman, P., Westra, L., and Abrams, E. 2009. *Comprehensive Peer Educator Training Curriculum, Trainer Manual, Version 1.0.*, International Center for AIDS Care and Treatment Programs.
- International Center for AIDS Care and Treatment Programs. 2010. *Improving Retention, Adherence, and Psychosocial Support within PMTCT Services, Implementation Workshop: A Toolkit for Health Workers*.
- WHO. 2010. Geneva, WHO Press.

### Advance Preparation



- Read through the entire module and ensure that all trainers are prepared and comfortable with the content and methodologies.
- Review the appendices and ensure all trainers are comfortable using them and integrating them into the module.

### **Session 8.1: Introduction to Retention and Adherence**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation, with large group discussion and brainstorming	25 minutes
Questions and answers	5 minutes
Total Session Time	30 minutes

### **Session 8.2: Supporting Retention and Adherence to Care**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation and large group discussion	10 minutes
Questions and answers	5 minutes
Total Session Time	15 minutes

### **Session 8.3: Providing Adherence Preparation Support to ALHIV and Caregivers**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation and large group discussion	60 minutes
Exercise 1: Developing an Adherence Plan: Case studies in small groups and large group discussion	55 minutes
Questions and answers	5 minutes
Total Session Time	120 minutes

### **Session 8.4: Assessing Adherence and Providing Ongoing Adherence Support**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation and large group discussion	10 minutes
Exercise 2: Assessing Adherence and Providing Support: Role play and large group discussion	50 minutes
Questions and answers	5 minutes
Review of Key Points	10 minutes
Total Session Time	75 minutes

## Session 8.1 Introduction to Retention and Adherence



**Total Session Time:** 30 minutes



### Trainer Instructions

Slides 1-5

**Step 1:** Begin by reviewing the Module 8 learning objectives and the session objectives, listed below.

**Step 2:** Ask participants if there are any questions before moving on.

### Session Objectives

**After completing this session, participants will be able to:**

- Define retention in, and adherence to, HIV care and treatment.
- Identify common barriers to retention in care and adherence to treatment among adolescent clients.



### Trainer Instructions

Slides 6-12

**Step 3:** Explain to participants that retaining ALHIV in care and supporting ALHIV's adherence to both HIV care and treatment is one of the most important, and challenging, tasks healthcare workers face.

**Step 4:** Write "**RETENTION**," "**ADHERENCE TO HIV CARE**," and "**ADHERENCE TO MEDICATIONS**" on flip chart paper. Ask participants to list what we mean by each of these terms or phrases. Record participants' answers on flip charts and fill in using the information below.

Then write "**NON-ADHERENCE**" on a piece of flip chart and ask participants to discuss what this phrase means. Record participants' responses on the flip chart and fill in using the content below.

Lastly, ask participants:

- *Why is excellent adherence to care and treatment important for ALHIV?*

**Step 5:** Debrief by reminding participants that healthcare workers and health systems play a key role in retaining clients in care. Also explain that adherence support to ALHIV and their caregivers should be ongoing — not one-time events — and that the entire multidisciplinary team is responsible for providing these services.



### **Make These Points**

- Retention refers to keeping (or “retaining”) clients in the care programme, in this case continuing with lifelong HIV care and treatment services. For adolescents, this also means transitioning them to adult care and treatment.
- Adherence means how faithfully people stick to the care and treatment plan. Adherence to treatment is important to lower the amount of HIV in the body and to make sure the client gets all the benefits that OI medicines and ARVs have to offer (feeling better, not getting sick, etc).
- In the context of ART, studies have shown that clients must take over 95% of the necessary doses to achieve the conditions for therapeutic success, i.e. clients should “stick” to at least 95% of their drug schedule. Therefore, as healthcare workers our aim is to support clients to achieve and sustain this rate of adherence to their regimens.
- Non-adherence to treatment can lead to drug resistance, preventing ART from working and making people very sick. Non-adherence can cause CD4 counts to decrease, opportunistic infections to occur, resistance to emerge, and viral replication to continue.
- Good adherence is achieved through a partnership between the caregiver, ALHIV, and the entire multidisciplinary care team.

## **Overview of Retention and Adherence**

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### **Definition of retention:**

- Retention refers to keeping (or “retaining”) clients in the care programme; in this case, the continuation with lifelong HIV care and treatment services.
- A goal of all HIV care and treatment programmes is to retain clients in care and treatment. The onus of retention is on healthcare workers and managers, as they can offer quality services and set up systems that support the retention of ALHIV.
- For ALHIV, this also means supporting their transition to adult care and treatment (see Module 12).

### **Definition of adherence:**

The standard clinical definition of adherence has been taking at least 95% of medications the right way, at the right time. Over time, this definition has been broadened to include more factors related to continuous care, such

as following a care plan, attending scheduled clinic appointments, picking up medicines on time, and getting regular CD4 tests.

### **Key concepts of adherence:**

- Includes active participation of the client in his or her care plan (and, if applicable, the active participation of caregivers in the client's care plan)
- Includes adherence to both medications and care
- Depends on a shared decision-making process between the client (and caregivers) and healthcare workers
- Determines the success of HIV prevention, care, and treatment programmes
- Is not static — in other words, it changes over time and as ALHIV age and go through different developmental stages and life changes

#### **Adherence**

Adherence describes how faithfully a person sticks to and participates in his or her HIV prevention, care, and treatment plan.

### **Adherence to care includes:**

- Entering into and continuing on a lifelong care and treatment plan
- Attending appointments and tests, such as regular CD4 tests, as scheduled
- Taking (or giving) medicines to prevent and treat opportunistic infections
- Participating in ongoing education and counselling
- Picking up medications when scheduled and before running out
- Recognising when there is a problem or a change in health and coming to the clinic for care and support
- Adopting a healthy lifestyle and trying to avoid risky behaviours, as much as is possible given the client's life situation

### **Adherence to treatment includes:**

- Taking (or giving) ARVs correctly, as prescribed, for the person's whole life, even if the person feels healthy ("every pill, every day")
- Taking (or giving) other medicines, such as CTX, as prescribed
- Not taking any treatment "breaks"

### **Non-adherence includes:**

- Missing one or many appointments at the hospital or health centre, lab, or pharmacy
- Not following the care plan
- Missing a dose or doses of medicine
- Sharing medications with other people
- Stopping medicine for a day or many days, or taking a "treatment break" or "holiday"
- Taking medicines at the wrong times

- Taking medicines without following instructions about timing or food intake

### **Why is excellent adherence to HIV care and medicines important?**

- To ensure that ART and other medications do their job — which is, to increase the CD4 cell count and decrease the amount of HIV in the body
- To make sure people get all the benefits that ARVs have to offer, such as feeling better, not getting sick as often or as badly, living a longer life, etc.
- To keep people looking and feeling good so they can get back to “normal” life, including going to school, working, socialising, and being an active family and community member
- To help adolescents grow and develop into healthy adults
- So the virus does not become resistant to certain medicines
- To prevent mother-to-child transmission of HIV
- To reduce the risk of spreading the virus to others
- To keep families and communities healthy and productive

**Remember, no one is perfect. It is important not to judge adolescent clients (and caregivers) if they are non-adherent. Instead, we should try to understand why people do not adhere and help clients and caregivers find ways to resume good adherence as soon as possible.**



#### **Trainer Instructions**

Slides 13-16

#### **Step 6:**

Post 4 pieces of flip chart, each with one of the following labels, around the training room (“**HEALTH SERVICES FACTORS,**” “**INDIVIDUAL FACTORS (about the adolescent),**” “**COMMUNITY AND CULTURAL FACTORS,**” “**MEDICINE FACTORS**”).

Explain to participants that they will do a brainstorming activity on the key factors affecting retention and adherence for ALHIV.  
Ask:

- *What are the most common retention and adherence issues for ALHIV?*
- *What are the most common factors for younger adolescents?*
- *How about for older adolescents?*

Using participant inputs, list relevant factors under each category and fill in from the content below. Remind participants that most clients **do** want to adhere to their care and treatment plan, but there are often barriers that get in the way.

- Step 7:** After this brainstorming activity, ask participants:
- *Which of these issues do you think has the greatest impact on an adolescent's retention and adherence? Why?*
- Step 8:** (optional) If willing and comfortable, ask the adolescent co-trainer to offer his or her opinion and to respond to the discussion questions in Step 7.
- Step 9:** Explain to participants that in the next session we will talk about specific actions that healthcare workers can do to support retention and adherence to care among their adolescent clients.



### **Make These Points**

- There are many barriers and challenges to retention and good adherence, including factors related to our client's lives, to the medicines, and to the health care system and HIV programme.
- There are many challenges to adherence that are more common in ALHIV: they engage in more risk taking behaviours, they have a desire to "fit in" with peers and appear "normal;" they may not take their medication to demonstrate defiance and a need to define their identity.
- We often blame clients for not adhering to care and treatment, but not having access to quality, youth-friendly health services is often one of the biggest barriers to retention and adherence.

## **Factors Affecting ALHIV Adherence**

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The following is a listing of some of the common factors that can affect adherence for adolescents.

### **Health service factors:**

The following health service factors can affect client adherence to treatment and retention in care.

- Availability of youth-friendly services
- Lack of confidentiality
- Provider attitudes
- Drug stock-outs
- Distance to the clinic/transportation costs
- Convenience of clinic hours
- Patient record and tracking systems
- Number and type of healthcare workers
- Provider language
- Waiting times
- Space for private counselling

- Linkages between services, including linkages to social and material support in the community and home-based care
- Referral systems
- Support groups
- PLHIV involvement, including ALHIV
- The cost of health services or medicines

### **Individual factors:**

Adolescence can bring with it some new issues that can affect adherence. Some adolescents — when going through a rebellious or risk-taking stage — want to define who they are, take more risks, and have a desire to “fit in” with peers and appear “normal”, all of which can negatively affect their adherence to care and medicines. Sometimes, young adolescents who have been managing well with HIV and adhering to their care and treatment (when their parents or caregivers took primary responsibility for their care) have new adherence challenges as they progress through adolescence and take on more responsibility for their own care.

The following are additional individual factors that can affect client adherence to treatment and retention in care.

- Feeling self-conscious about taking medication (particularly older adolescents).
- Forgetting to take their medicine; or, sometimes, forgetting because of alcohol or drug use.
- Side effects:
  - If a person feels sick from the medicine, then he or she is more likely to stop taking it.
  - If a person begins to notice unwanted body changes caused by the medicine (such as lipodystrophy — changes in fat distribution on different parts of the body), he or she may stop taking the medicine.
- Running out of tablets, forgetting to go to pharmacy at end of the month
- Having difficulty accepting his or her HIV status
- Stigma and discrimination from peers, family and/or others in community can affect willingness to take HIV medications or go to an HIV clinic, for fear that these behaviours might disclose their HIV status
- How far along they are in the disclosure process
- Whether or not they have adequate family or social support (i.e. no treatment “buddy” or supporter)
- How sick or well people feel
- Migration or relocation — disrupting continuity of care
- Time away from home, school, or work because of clinic appointments
- Mental illness, like depression

### **Community and cultural factors:**

The following are environmental factors (for example, families, communities, and culture) that can affect an adolescent client’s adherence to treatment and retention in care.

- Lack of family support or help with decision making from caregivers, particularly for younger adolescents
- Poverty
- Lack of food
- Stigma and discrimination
- Caregiver's availability, health, and understanding of adherence
- Societal discomfort with youth and issues related to HIV, like sexuality
- Disclosure within the family, or at school or work — either not disclosing so there is a lack of peer support or the fear that taking medications or leaving early to go to the clinic will inadvertently disclose one's HIV status
- Social support at home and in the community, including at school
- Unable to find child care for younger siblings (if youth-headed household) or for one's own children (if a young parent)
- Unable to take time off from school or work to attend clinic
- Gender inequality: In some places, young women are less likely to have access to adequate nutrition to support their treatment, they can be more dependent on others economically, they can sometimes be forced to share their treatment with others, and it may be harder for them to travel to clinics to access treatment.
- Violence
- Distrust of the clinic/hospital
- Use of traditional medicine — which can replace perceived need for ART or negatively interact with HIV-related medications
- Political instability or war
- Physical environment (for example, mountains, seasonal flooding, etc.)

### **Medicine factors**

The following are things about ARV medicines that can affect an adolescent client's adherence to treatment and retention in care.

- Side effects
- Changing paediatric doses
- Changing regimens
- Number of pills in regimen
- Dose timing
- Availability of reminder cues — pill boxes, calendars, alarms, etc.
- Taste
- Changes in drug supplier — labelling, pill size, colour, formulation



#### **Trainer Instructions**

**Step 10:** Allow 5 minutes for questions and answers on this session.

## Session 8.2      Supporting Retention and Adherence to Care

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**Total Session Time:**      15 minutes



### **Trainer Instructions**

Slides 19-20

- Step 1:**      Begin by reviewing the session objective listed below.
- Step 2:**      Ask participants if there are any questions before moving on.

### **Session Objective**

**After completing this session, participants will be able to:**

- Discuss ways that healthcare workers and health facilities can support adolescents' retention in and adherence to care.



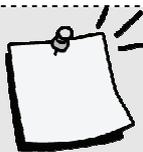
### **Trainer Instructions**

Slides 21-24

- Step 3:**      Explain that while we, as healthcare workers, are not always able to address all of the client's barriers to adherence, there are many factors that we **CAN** address in order to support clients' retention and adherence to care.
- Ask participants to brainstorm the ways they can think of for healthcare workers to minimise the barriers to retention and adherence to care that were discussed in the last session (refer to the flip chart on "**HEALTH SERVICES FACTORS**" from the last session). This includes actions that individual healthcare workers can take, as well as actions taken at the facility or systems levels. Write answers on flip chart and fill in using the content below.
- Step 4:**      Next, ask participants to think about the facility where they work. Lead a discussion about the specific actions for improving retention, using the following questions as a guide:
- *Which of these areas are lacking at your facility?*
  - *How could these areas be improved to better support ALHIV's retention in care at your facility?*
  - *What are some of the challenges to implementing these actions? What are some of the solutions?*

Participants should feel free to refer to their partly completed “Appendix 2B: Checklist and Assessment Tool for Youth-Friendly HIV Care and Treatment Services” discussed during Exercise 2 in Module 2. This assessment tool can provide some insight in making services more youth-friendly, which in turn has a direct affect on retention in care.

**Step 5:** (optional) Ask the adolescent co-trainer to comment on some of the reasons that ALHIV may not be retained in care and what he or she thinks healthcare workers and health facilities can do to help retain clients over the long-term.



### **Make These Points**

- Although it is ultimately the responsibility of clients to adhere to their care plans, there are many steps healthcare workers can take to make it easier for clients to adhere to care.
- One of the most important steps to improve retention in care is to ensure that services are youth friendly. Refer to “Appendix 2B: Checklist and Assessment Tool for Youth-Friendly HIV Care and Treatment Services” in Module 2 for a listing of the characteristics of youth-friendly services.
- Some suggestions to make services youth friendly include: offering services at times when adolescents can attend (after school and weekends); ensuring staff are friendly, non-judgemental, and respectful; establishing an appointment system to reduce waiting time. A CAB (community advisory board) can provide further guidance to ensure services meet the needs of adolescent clients.
- Services that are youth friendly increase the likelihood of attendance and therefore the likelihood of perfect, or near-perfect adherence to treatment.

## **Improving Retention in and Adherence to Care**

The following are suggestions for healthcare workers to improve retention in and adherence to care among ALHIV.

- Ensure HIV services are youth-friendly and that adolescent clients are treated respectfully and non-judgementally by healthcare workers
- Ensure that HIV services are provided on days and times that are convenient to adolescent clients
- Use a developmental, youth-friendly approach to counselling and education that corresponds to the adolescent’s maturational stage
- Build a relationship of trust and respect with clients
- Ensure linkages to adolescent Peer Educators and adolescent support groups

- Make time for private counselling and adherence support sessions and ensure adolescent client’s privacy and confidentiality.
- Ensure that there are appointment systems in place.
- Ensure that all clients are given reminder cards to help them remember their upcoming appointments.
- Ensure that there are systems to track adolescent clients who miss clinic appointments or pharmacy refills.
- Track client attendance. When adolescent clients miss an appointment, contact them through phone calls or SMS messaging. If that does not work, or isn’t available as an option, send an outreach worker to their homes (or to the home of their treatment buddy; treatment buddies are discussed in Session 8.3) to provide counselling and education and to set an appointment for their next visit.\*
- Check in with clients frequently after starting or changing medications — if not medical visits then by phone or outreach.
- If possible, provide transportation stipends to clients who are unable to pay for their own transportation to the clinic.
- Consider establishing a formal mechanism to facilitate feedback from clients through the establishment of an adolescent consumer (or client) advisory board (CAB). CABs are autonomous bodies that advise the clinic on quality of services, gaps in care and make recommendations to improve service provision. CABs are discussed further in Module 11.

See also “Appendix 2B: Checklist and Assessment Tool for Youth-Friendly HIV Care and Treatment Services” in Module 2, which is an audit of services. The outcome of this assessment tool can provide additional suggestions to make a clinic friendlier for adolescents.

**\*Permission to call or visit home**

During the baseline intake and at key times thereafter, perhaps annually, ensure personal client information — such as address and phone numbers — are updated. At that time, request permission to follow up by phone or home visit should the client miss a clinic visit. Clients who have not disclosed their HIV status to others in the home may give special instructions at that time regarding what to say to caregivers or siblings regarding the nature of the visit.



**Trainer Instructions**

**Step 6:** Allow 5 minutes for questions and answers on this session.

## Session 8.3

# Providing Adherence Preparation Support to ALHIV and Caregivers



**Total Session Time:** 120 minutes (2 hours)



### Trainer Instructions

Slides 25-26

- Step 1:** Begin by reviewing the session objective listed below.
- Step 2:** Ask participants if there are any questions before moving on.

### Session Objective

**After completing this session, participants will be able to:**

- Conduct adherence preparation sessions with adolescents who are starting ART, and their caregivers.



### Trainer Instructions

Slides 27-30

- Step 3:** Remind participants that some of their adolescent clients will have been on ART for many years and some will just be starting ART. In this session, we will focus on adolescent clients who are starting ART, and their caregivers.
- Step 4:** Provide an introduction to adherence preparation by giving an overview of the process. Ask participants the following questions and record responses on a flip chart:
- *In your clinics, is adherence preparation undertaken in individual or in group sessions?*
  - *Who facilitates these sessions?*
  - *What is a treatment buddy and how might a treatment buddy help an adolescent client?*



### Make These Points

- ART preparation usually includes group education sessions, individual

counselling sessions, and an adherence readiness assessment.

- Each client should have AT LEAST one individual counselling session with a healthcare worker (and/or other members of the multidisciplinary team, such as a Peer Educator or counsellor) before starting ART.

## **Adolescent-Friendly ART Adherence Preparation**

Overview of adherence preparation and support for clients and caregivers:

- The “Zambia Adult and Adolescent Antiretroviral therapy Protocols, 2010”, recommend a total of 3 adherence preparation visits. Although the 1<sup>st</sup> and 2<sup>nd</sup> adherence preparation visits may be conducted within a group session, the 3<sup>rd</sup> of the 3 visits should include an individual counselling session. Another member of the multidisciplinary care team, like a Peer Educator or counsellor, can assist the healthcare worker during these sessions.
- ALHIV initiating care and treatment should have time to speak to a counsellor, healthcare worker, and/or Peer Educator alone, and in private.
- The counselling session should include talking with the client (and caregiver or treatment buddy) about any adherence challenges they may face and making an individual adherence plan.
- Group education/peer support sessions are useful in giving many people information at one time.
- An individual session can be used to find out what the client (and caregiver) has learned from any group education sessions, and in which areas they need extra support.
- While providing as much support as possible, the multidisciplinary care team should be flexible when addressing ART readiness. The preparation process should facilitate ART initiation and should never be a barrier.

### **What is a treatment buddy?**

A **treatment buddy** or **treatment supporter** is someone who is chosen by a client about to start ART to provide ongoing support for adherence to care and treatment.

A treatment buddy is usually a client’s caregiver, friend, family member, or another ALHIV who is also enrolled in care and is a trusted person to whom a client can disclose her or his status. Younger adolescents may have one of their primary caregivers as a treatment buddy. Older adolescents may prefer to have a friend or peer as their treatment buddy, but it depends on the client.

Generally, a treatment buddy receives some basic education on HIV, adherence, and positive living, and can then provide psychosocial and

adherence support to an adolescent client. It is important for healthcare workers, including Peer Educators, to explain to ALHIV the importance of having a treatment buddy and to make sure that treatment buddies have the information and skills needed to support adherence and positive living. **Remember, not having a treatment buddy should not act as a barrier to any client initiating ART.**



### Trainer Instructions

Slides 31-43

#### Step 5:

Explain that we are now going to discuss the importance of adherence preparation and assessing readiness to start ART. Ideally adherence readiness assessment and counselling should begin early in HIV care, but should not be a reason to delay initiation of ART in most ALHIV. It is important for healthcare workers to provide initial adherence preparation education and support, but most of all, to give ongoing adherence support to ALHIV and their caregivers — over time and at every clinic visit.

Ask participants the following questions and record responses on a flip chart:

- *What happens in your clinic now to prepare adolescent clients and caregivers to start ART? What do you think works well? What are some of the challenges?*
- *What topics do you think should be covered in adherence preparation with ALHIV and caregivers?*
- *What are some considerations for younger adolescents in terms of adherence readiness and preparation?*

#### Step 6:

Provide an overview of the 3 adherence preparation visits as outlined in the Zambia “Adult and Adolescent Antiretroviral Therapy Protocols, 2010” and described in the content below.

Start by asking:

- *The national guidelines recommend a minimum of 3 adherence preparation visits. What do you think should take place during the 1<sup>st</sup> visit?*

Fill in using the content below and “Appendix 8A: Key Points — Adherence Preparation Visit 1”. Have one participant read the 10 topics in Appendix 8A (numbered 1 to 10, all of which are questions in black rows with white font). Have participants brainstorm the key points for each topic, where the key points are not obvious (the trainer need not go over every key point, but should take the time to go over the key points that are more

complex).

Then ask:

- *What do you think should take place during the 2<sup>nd</sup> visit?*

Provide an outline of the 2<sup>nd</sup> adherence preparation visit, using the content below and “Appendix 8B: Key Points — Adherence Preparation Visit 2”. Again, ask a participant to read the 10 topics (numbered 1 to 10, most of which are questions — all of which are in black rows with white font). Have participants brainstorm the key points for each topic, where the key points are not obvious (the trainer need not go over every key point, but should take the time to go over the key points that are more complex).

And, finally ask:

- *What do you think should take place during the 3<sup>rd</sup> visit?*
- *Now that you have seen the guidelines for all 3 adherence preparation visits, how do you think you could use these tools in your work/clinic?*

Provide an outline of the 3<sup>rd</sup> adherence preparation visit, using the content below and “Appendix 8C: Key Points — Adherence Preparation Visit 3”. Again, ask a participant to read the 5 topics (numbered 1 to 5, all of which are framed as question and formatted in black rows with white font). Have participants brainstorm the key points for each topic, where the key points are not obvious (the trainer need not go over every key point, but should take the time to go over the key points that are more complex).

Tell participants that the key points for the 3 adherence preparation visits are listed in Appendices 8A, 8B and 8C as well as the Zambia “Adult and Adolescent Antiretroviral Therapy Protocols, 2010”. As this material is covered in other training courses, we will not spend much time on it today, but those of you hearing about the adherence preparation visits for the 1<sup>st</sup> time today, should mark these 3 appendices and plan to revisit them after the training.

**Step 7:** Review “Tips for developing a personal adherence plan” which provides guidance for supporting clients to develop a personal adherence plan during the 3<sup>rd</sup> adherence preparation visit.

Ask participants

- *What do we need to ask clients (and their caregivers) to encourage them to develop their personal adherence plan?*
- *What are some considerations for younger adolescents in terms of adherence readiness and preparation?*
- *What is a treatment buddy?*

- Step 8:** Review with participants “Appendix 8D: Adherence Preparation and Support Guides”. Discuss how to conduct a readiness assessment. Ask participants:
- *How could this assessment be modified for different ages of adolescents?*
  - *How do you think you could use this tool in your work/clinic?*
- Step 9:** (optional) If willing and comfortable, ask the adolescent co-trainer to talk about his or her experiences starting ART (assuming he or she started ART as an adolescent, not as a baby). For example, the adolescent co-trainer could discuss the following:
- *Can you remember when you started ART? What kind of education and support did you and/or your caregivers receive at the clinic?*
  - *What were your concerns about starting ART? Do you remember if your caregiver had concerns as well?*
  - *What was good about the adherence preparation you received? What could have been better?*
  - *Do you have a treatment buddy? How does he or she help?*



### Make These Points

- The Zambia “Adult and Adolescent Antiretroviral Therapy Protocols, 2010” recommend a minimum of 3 adherence preparation visits, as part of a structured treatment preparation plan prior to initiating ART.
- Young adolescents, where and when possible should be accompanied by a caregiver, or someone else who can provide support, during these sessions.
- When helping clients and caregivers prepare for ART, healthcare workers should always address the ARE YOU COMMITTED and then the WHO, WHAT, WHEN, WHERE and HOW of the medications.
- A standardised assessment tool can help determine a client and caregiver’s readiness for ART and help them to form an adherence plan. **The assessment questions should be used to identify areas where the client and/or caregiver may need additional information and support.** It should not be used as a ‘test’ that the client needs to pass before he or she can begin ART.
- Treatment buddies can be especially helpful for adolescent clients. A treatment buddy or treatment supporter is someone who is chosen by a client about to start ART to provide ongoing support for adherence to care and treatment.

## **ART Adherence Preparation**

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The Zambia “Adult and Adolescent Antiretroviral Therapy Protocols, 2010” recommend a minimum of 3 adherence preparation visits, as part of a structured treatment preparation plan prior to initiating ART. These adherence preparation visits are designed for the adolescent client who was diagnosed with HIV as a young adult (i.e., not as an infant or child). Young adolescents, where and when possible should be accompanied by a caregiver, or someone else who can provide support, during these sessions.

### **Adherence preparation visit 1**

The 1<sup>st</sup> adherence preparation visit is typically attended by the client who has recently received a positive HIV test and has enrolled in care. It is during this visit that the client will learn about HIV and AIDS, how HIV is transmitted/prevented, disclosure, partner referral and testing, CD4, viral load, CTX and ART.

The topics and key points for Adherence preparation visit 1 can be found in “Appendix 8A: Key Points — Adherence Preparation Visit 1”.

### **Adherence preparation visit 2**

The 2<sup>nd</sup> adherence preparation visit is for clients who have undergone clinical and laboratory assessment and found to qualify for ART. Adherence preparation visit 2 may take place weeks, months or years after adherence preparation visit 1. During this visit clients will learn about ART, starting ART, benefits of ART, resistance, preventing resistance and the importance of excellent adherence.

#### **Adherence preparation visits 1, 2 and 3**

- These sessions can be conducted by any qualified trained personnel (medical officer, medical licentiate, clinical officer, nurse, adherence counsellor, community worker).
- The key points for the adherence preparation visits can be covered in an individual or group session. If utilising a group session format, establish ground rules emphasizing the importance of keeping the discussion and names of other group members confidential.

The topics and key points for Adherence preparation visit 2 can be found in “Appendix 8B: Key Points — Adherence Preparation Visit 2”.

### **Adherence preparation visit 3**

The 3<sup>rd</sup> adherence preparation visit is for the client who is free of any opportunistic infections or is on treatment for OIs and has been prescribed ART. During this visit the client will learn more about resistance and how to develop a successful adherence plan. They should also take the “Patient Readiness Questionnaire” as either part of the group session or in the individual counselling session.

The topics and key points for Adherence preparation visit 3 can be found in “Appendix 8C: Key Points — Adherence Preparation Visit 3”. Appendix 8C also includes the “Patient Readiness Questionnaire”.

## **Personal adherence plan**

### **Tips for developing a personal adherence plan**

During the individual counselling session, work with clients to develop a personal adherence plan. This plan should address the ARE YOU COMMITTED and then the WHO, WHAT, WHEN, WHERE, and HOW of the medications:

- **ARE YOU PLANNING TO TAKE YOUR MEDICATIONS?** If the response to this question is no, then consider delaying ART initiation.
- **WHO** will help you remember to take your medicine every day at the same time? Is there someone who can help you come to the clinic for appointments?
- **WHAT** medicines are you taking? What is the dose and how often will you take it? What will you do when you are about to run out of your medicines? What will you do if you miss a dose of your medicine?
- **WHEN** will you take your medication? Establish a routine.
- **WHERE** will you take your doses of ARVs (for example, school, home, work, etc.)? Where will you store your ARVs?
- **HOW** will you remember to take your medicines at the same time, every day? When you are at school or work? When you are away from home? When you are with your family? When you are with your friends?

### **Assessing clients’ and caregivers’ readiness for ART**

Use the plan agreed during the WHO, WHAT, WHEN, WHERE, and HOW discussions when completing the “Guide for Assessing Adolescents’/Caregivers’ Readiness for ART” questionnaires in Appendix 8D: Adherence Preparation and Support Guides”. These assessment guides are standardised tools that can help healthcare workers assess a client’s and caregiver’s readiness for ART. The guides can also:

- Support healthcare workers to increase their clients’ understanding of the importance of lifelong adherence to HIV care and treatment.
- Ensure a shared understanding of the care and medications plan.
- Identify potential adherence challenges and brainstorm practical solutions.

Instructions for administering the guides are also included as part of Appendix 8D.

Note that it may take 1, 2, or more individual counselling sessions before the client is ready to start ART. Upon completion of the 3 adherence preparation visits and the individual counselling session or sessions, the client should be ready to initiate ART. If the client is not ready, the multidisciplinary teams can advise if the client should delay initiation until

the next visit, or discuss their reservations with the client and/or the caregiver and give them the choice to start now or delay temporarily.

Keep in mind that, as with any other one-to-one counselling session, the client will need to be reminded that the session is confidential. When counselling adolescents, also remind them that the commitment to confidentiality also means that the healthcare worker will not share with a caregiver or partner the information discussed in the individual counselling session.



### Trainer Instructions

Slides 44-50

**Step 10:** Lead participants through Exercise 1, which gives an opportunity to practise and discuss conducting adherence preparation sessions and readiness assessments with adolescent clients and caregivers.

### Exercise 1: Developing an Adherence Plan: Case studies in small groups and large group discussion

<b>Purpose</b>	<ul style="list-style-type: none"> <li>To practise conducting adherence preparation counselling, including an adherence readiness assessment, with adolescent clients and caregivers.</li> </ul>
<b>Duration</b>	55 minutes
<b>Advance Preparation</b>	<ul style="list-style-type: none"> <li>Review the case studies and make adjustments, as needed.</li> <li>Be prepared to explain how to present the checklists in “Appendix 8A: Key Points — Adherence Preparation Visit 1”, “Appendix 8B: Key Points — Adherence Preparation Visit 2”, and “Appendix 8C: Key Points — Adherence Preparation Visit 3”. Also be prepared to explain how to administer “Appendix 8D: Adherence Preparation and Support Guides”.</li> </ul>
<b>Introduction</b>	<p>Explain that in this activity we are going to explore how to educate, counsel, prepare, and assess readiness of adolescent clients (and caregivers) who are preparing to start taking ART.</p> <p>Ask participants to review the case studies in their participant manuals. Refer participants to “Appendix 8A: Key Points — Adherence Preparation Visit 1”, “Appendix 8B: Key Points — Adherence Preparation Visit 2”, “Appendix 8C: Key Points — Adherence Preparation Visit 3”, and “Appendix 8D: Adherence Preparation and Support Guides”.</p>
<b>Activities</b>	<p><b>Part 1: Trainer Demonstration</b></p> <ol style="list-style-type: none"> <li>The trainer should start the activity by role playing Case</li> </ol>

	<p>Study 1, below, with 2 volunteer participants (or 1 volunteer participant and the adolescent co-trainer). The trainer plays the role of the healthcare worker who will assist the client to develop an adherence plan. The volunteers play a caregiver and an adolescent who is about to start ART. The other participants are asked to observe the counselling session and ask questions (approximately 20 minutes).</p> <p>2. (optional) Encourage participation from the adolescent co-trainer. Ask the following questions to encourage his or her participation:</p> <ul style="list-style-type: none"> <li>• <i>What did the healthcare worker do to build trust and rapport with the client?</i></li> <li>• <i>What were the key ART readiness issues for this client? How did the healthcare worker respond?</i></li> <li>• <i>Can you summarise the final adherence plan agreed for this client?</i></li> <li>• <i>Based on your own experience, is there anything else the healthcare worker could have suggested or done to address the client's adherence challenges?</i></li> </ul> <p><b>Part 2: Small Group Work</b></p> <p>3. Next, break participants into 4 small groups and assign each a case study. Ask participants to respond to the questions at the end of their case study.</p> <p><b>Part 3: Large Group Discussion</b></p> <p>4. Bring the large group back together and ask each group to summarise their case study discussions. If time allows, invite 1 or 2 of the groups to conduct a short role play in front of the large group. Ask the following questions to facilitate discussion and record responses on a flip chart (approximately 15 minutes):</p> <ul style="list-style-type: none"> <li>• <i>How did you determine an adherence plan with the client or caregiver? How would you measure its success or outcome?</i></li> <li>• <i>Did you have any concerns about the client initiating ART? How would you address this with the client and/or caregiver?</i></li> <li>• <i>What advice did you give to the client about adherence to care and medicines? The caregiver?</i></li> </ul>
<p><b>Debriefing</b></p>	<ul style="list-style-type: none"> <li>• As healthcare workers, one of our most important tasks is to provide adherence preparation counselling and support to our adolescent clients and their caregivers.</li> <li>• Group sessions are helpful for providing the content of adherence preparation visit 1, 2 and 3, but individual sessions are also required to explore and discuss</li> </ul>

	<p>clients' specific situations and to make an individual adherence plan with clients and their caregivers.</p> <ul style="list-style-type: none"> <li>• Remember, when helping clients and caregivers to develop an adherence plan, healthcare workers should always address the WHO, WHAT, WHEN, WHERE, and HOW of the medications.</li> <li>• Using standardised assessment tools (such as those in Appendix 8D) can help determine a client and caregiver's readiness for ART and help them to form an adherence plan.</li> </ul>
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**Exercise 1: Conducting an Adherence Readiness Assessment: Case studies in small groups and large group discussion**

**Case Study 1:**

Bupe is 11 years-old and will begin taking ART today. Today is her 3<sup>rd</sup> adherence preparation visit and she and her Auntie have gone through the 3 group presentations. Auntie is her primary caregiver and will be responsible for giving Bupe her medicines every day. Bupe understands that she has HIV and needs to take medicines everyday, but Auntie is worried how she will manage. How should you help Bupe and her caregiver prepare for adherence at the clinic today? What questions would you ask to assess their understanding of adherence and readiness for Bupe to start ART?

**Key points for trainers: Bupe**

- Start by asking Bupe and Auntie what questions they have so far. Go over some of the key topics covered during adherence preparation visits 1, 2 and 3 just to make sure they understood (for example: "I see your CD4 count is 350, can you tell me what the CD4 cell is?" "I see you are on CTX, can you remember what CTX does?" "We are going to start you on ART, can you tell me how you think ART will help you?" "Why do you think excellent adherence is so important?"). Administer the "Patient Readiness Questionnaire" if it was not already administered in the group session. Emphasize the relationship between poor adherence and resistance.
- Then start working with Bupe and Auntie to develop a personal adherence plan by asking the ARE YOU COMMITTED and (assuming Bupe reassures you that she is planning to take her ARVs) then ask the WHO, WHAT, WHEN, WHERE, and HOW questions.
- Administer the "Adherence Preparation/Support Guide for Assessing Adolescents' Readiness for ART" to Bupe and the "Adherence Preparation/Support Guide for Assessing Caregivers' Readiness for ART" to Auntie. Administer the guides to each separately, feel free to skip questions that were answered during the WHO, WHAT, WHEN, WHERE and HOW discussion. Where their answers for parallel

questions differ greatly, discuss with both of them together.

- As Bupe is only 11, ensure that Auntie is ready to take an active role in assuring Bupe's adherence is excellent.
- Take note (on paper) of key points as you go along, reassure Bupe and Auntie that this is the right decision and that you are confident in Bupe's ability to adhere to her medicines with Auntie's help. Summarise the key points (using your notes) along with next steps as you close the discussion.

### **Case Study 2:**

Saasa is 16 years old and lives on his own. He needs to start taking ART and the doctor asks you to help prepare him for adherence, now that he has attended the 3 adherence preparation visits. Saasa works during the day as a taxi assistant and you sense that it might be challenging for him to take his medicines the right way because he has not disclosed to anyone and he works long hours. How do you help Saasa prepare to start taking ART? What questions would you ask to assess his readiness for ART?

#### **Key points for trainers: Saasa**

- Start by asking Saasa what questions he has so far. Go over some of the key topics covered during adherence preparation visits 1, 2 and 3 just to make sure he understood (for example: "I see your CD4 count is 350, can you tell me what the CD4 cell is?" "I see you are on CTX, can you remember what CTX does?" "We're going to start you on ART, can you tell me how you think ART will help you?" "Why do you think excellent adherence is so important?"). Administer the "Patient Readiness Questionnaire" if it was not already administered in the group session. Get him to do most of the talking, ensure he understand the relationship between poor adherence and resistance.
- Then start working with Saasa to develop a personal adherence plan by asking the ARE YOU COMMITTED and (assuming Saasa reassures you that he is planning to take his ARVs) then ask the WHO, WHAT, WHEN, WHERE, and HOW questions.
- Pay special attention to his response to the "WHO" question. It's quite likely that he won't have anyone to help him to remember to take his medications. This is OK....so long as you are satisfied that he has other ways to remember.
- Also pay attention to his responses to the "WHEN", "WHERE" and "HOW" questions. Work with him to ensure that he can come up with a sustainable routine given his lifestyle. Apply any tricks he uses to adhere to CTX to his plan for adhering to ART.
- Make sure he knows what to do should he miss a dose.
- Reassure him that any 16-year-old responsible enough to hold down a job can certainly apply those same skills to taking his medicine every day.
- Administer the "Adherence Preparation/Support Guide for Assessing

Adolescents' Readiness for ART" to Saasa. Feel free to skip questions that were answered during the WHO, WHAT, WHEN, WHERE and HOW discussion.

- Take note (on paper) of key points as you go along, reassure Saasa that this is the right decision and that you are confident in Saasa's ability to adhere to his medicines. Summarise the key points (using your notes) along with next steps as you close the discussion.

### **Case Study 3:**

Lumamba is 17 years old and lives with her mother and father. She is going to start taking ART and, now that she has attended the 3 adherence preparation visits, you have been asked to help prepare her and make an adherence plan. Lumamba is at the clinic with her older cousin and says she and her mother and father do not talk much about HIV. Her cousin has agreed to be her treatment supporter. How would you prepare Lumamba and her cousin to start taking ART? What questions would you ask to assess their readiness and understanding?

### **Key points for trainers: Lumamba**

- Start by asking Lumamba and Cousin what questions they have so far. Go over some of the key topics covered during adherence preparation visits 1, 2 and 3 just to make sure they understood (for example: "I see your CD4 count is 350, can you tell me what the CD4 cell is?" "I see you are on CTX, can you remember what CTX does?" "We're going to start you on ART, can you tell me how you think ART will help you?" "Why do you think excellent adherence is so important?"). Administer the "Patient Readiness Questionnaire" if it was not already administered in the group session. Emphasize the relationship between poor adherence and resistance.
- Then start working with Lumamba and Cousin to develop a personal adherence plan by asking the ARE YOU COMMITTED and (assuming Lumamba reassures you that she is planning to take her ARVs) then ask the WHO, WHAT, WHEN, WHERE, and HOW questions.
- Ask about disclosure, obviously Lumamba's cousin knows that she has HIV, but how about her parents? Can her parents assist at all or do the medicines have to be hidden at all times?
- Administer the "Adherence Preparation/Support Guide for Assessing Adolescents' Readiness for ART" to Lumamba and the "Adherence Preparation/Support Guide for Assessing Caregivers' Readiness for ART" to Cousin. Administer the guides to each separately, feel free to skip questions that were answered during the WHO, WHAT, WHEN, WHERE and HOW discussion. Where their answers for parallel questions differ greatly, discuss with both of them together. Given that Lumamba and Cousin do not live together, ask how they will ensure ongoing communication.
- Take note (on paper) of key points as you go along, reassure

Lumamba and Cousin that this is the right decision and that you are confident in Lumamba's ability to adhere to her medicines with Auntie's help. Summarise the key points (using your notes) along with next steps as you close the discussion.

#### **Case Study 4:**

Jane is 14 years old and, based on her CD4 results, is eligible to start ART. She is at the clinic for adherence preparation (she has already attended adherence preparation visits 1, 2 and 3) and initiation, accompanied by her father. Her mother recently passed away, so her father will be her main treatment supporter. While conducting adherence preparation counselling with Jane and her father, he expresses some concern that ART is bad for children and that his daughter feels fine without medicine. He also says that he works long hours away from the house, so Jane spends a lot of time at home with her older brother. How would you proceed in preparing Jane and her father for ART?

#### **Key points for trainers: Jane**

- Start by addressing Father's concern about ART. Discuss what will happen to Jane if she does not go on ART, versus what happens to clients who do go on ART. Consider pairing Father with the parent of other ALHIV who are on ART, so that he can hear about the benefits of ART from a peer. If there are local community or church leaders that are vocal about the advantages of ART, ask that he discuss the subject with those leaders. Consider delaying initiation until the next visit if you think it might help.
- Then ask Jane and Father what (other) questions they have so far. Go over some of the key topics covered during adherence preparation visits 1, 2 and 3 just to make sure they understood (for example: "I see your CD4 count is 350, can you tell me what the CD4 cell is?" "I see you are on CTX, can you remember what CTX does?" "We are going to start you on ART, can you tell me how you think ART will help you?" "Why do you think excellent adherence is so important?"). Administer the "Patient Readiness Questionnaire" if it was not already administered in the group session. Emphasize the relationship between poor adherence and resistance.
- Then start working with Jane and Father to develop a personal adherence plan by asking the ARE YOU COMMITTED and (assuming Jane reassures you that she is planning to take her ARVs) then ask the WHO, WHAT, WHEN, WHERE, and HOW questions.
- When discussing "WHO" ("*Is there someone who can help you come to the clinic for appointments?*"), discuss Father's role. Enquire about Father's extensive travel commitments and she how they want to work about that. Ask if there is anyone else who can act as her treatment buddy when Father is absent? Does her older brother know she has HIV? If so, could he take on this role?
- Administer the "Adherence Preparation/Support Guide for Assessing

Adolescents' Readiness for ART" to Jane and the "Adherence Preparation/Support Guide for Assessing Caregivers' Readiness for ART" to Father. Administer the guides to each separately, feel free to skip questions that were answered during the WHO, WHAT, WHEN, WHERE and HOW discussion. Where their answers for parallel questions differ greatly, discuss with both of them together.

- Take note (on paper) of key points as you go along, reassure Jane and Father that this is the right decision and that you are confident in Jane's ability to adhere to her medicines. Summarise the key points (using your notes) along with next steps as you close the discussion.

### **Case Study 5:**

Noah is 15 years old and lives with his mother and 4 younger siblings. Noah is still in school, but only because his mother requires him to go. Noah would prefer to spend his time with his friends, which he does do as soon as school ends. He is rarely home before 21.00hrs. He is failing nearly half of his classes. He has not told his mother or siblings of his HIV status, but he has told his best friend and partner, Aaron. Aaron is 21 and also has HIV. How do you help Noah prepare to start taking ART? What questions would you ask to assess his readiness for ART?

### **Key points for trainers: Noah**

- Start by asking Noah what questions he has so far. Go over some of the key topics covered during adherence preparation visits 1, 2 and 3 just to make sure he understood (for example: "I see your CD4 count is 350, can you tell me what the CD4 cell is?" "I see you are on CTX, can you remember what CTX does?" "We're going to start you on ART, can you tell me how you think ART will help you?" "Why do you think excellent adherence is so important?"). Get him to do most of the talking, ensure he understand the relationship between poor adherence and resistance. Administer the "Patient Readiness Questionnaire" if it was not already administered in the group session. Assess his commitment to ART.
- Then start working with Noah to develop a personal adherence plan by asking the ARE YOU COMMITTED and (assuming Noah reassures you that he is planning to take his ARVs) then ask the WHO, WHAT, WHEN, WHERE, and HOW questions.
- Pay special attention to his response to the "WHO" question. Now that you know his partner, Aaron, is HIV-infected, ask if Aaron is on ART. If not, ensure Aaron is in care; if so, consider suggesting Aaron as a treatment buddy. Recommend that Aaron accompany him to his next visit. Consider postponing the remaining points of this counselling session to the next visit when Aaron can accompany him.
- Pay attention to his responses to the "WHEN", "WHERE" and "HOW" questions. Work with him to ensure that he can come up with a sustainable routine given his lifestyle. Apply any tricks he uses to

adhere to CTX to his plan for adhering to ART. Apply lessons learned from missed doses of CTX to his plan for adhering to ART.

- Given Noah's lack of commitment to school, we might want to listen carefully for suggestion that he's not committed to his long-term health. Ensure he knows that by living positively he can have a normal life. Discuss safer sex, give him condoms and show him how to use them if he doesn't already know.
- Make sure he knows what to do should he miss a dose.
- Administer the "Adherence Preparation/Support Guide for Assessing Adolescents' Readiness for ART" to Noah. Feel free to skip questions that were answered during the WHO, WHAT, WHEN, WHERE and HOW discussion.
- Take note (on paper) of key points as you go along, reassure Noah that this is the right decision and that you are confident in Noah's ability to adhere to his medicines. Summarise the key points (using your notes) along with next steps as you close the discussion.



### **Trainer Instructions**

**Step 11:** Allow 5 minutes for questions and answers on this session.

## Session 8.4      Assessing Adherence and Providing Ongoing Adherence Support



**Total Session Time:** 75 minutes (1 hour, 15 minutes)



### Trainer Instructions

Slides 51-52

- Step 1:** Begin by reviewing the session objectives listed below.
- Step 2:** Ask participants if there are any questions before moving on.

### Session Objectives

**After completing this session, participants will be able to:**

- Assess adolescent clients' (and caregivers) adherence.
- Provide ongoing, age-appropriate support to improve adolescent clients' (and caregivers) adherence.



### Trainer Instructions

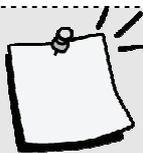
Slides 53-57

- Step 3:** Ask participants the following questions to facilitate discussion. Record responses on a flip chart.
- *How do you currently assess adherence in your clinic — with clients? With caregivers? What is good/challenging about this?*
  - *How do you think we can assess adherence?*
  - *What questions would you ask? What other methods (for example, pill count) would you use to assess adherence?*
- Briefly review some of the methods used to assess adherence using the content below.
- Step 4:** (optional) Ask the adolescent co-trainer the following questions to encourage participation:
- *What challenges have you or adolescents that you know had with adherence?*
  - *When/why is it most difficult to remember your medications?*
  - *How can healthcare workers support ALHIV with adherence?*

**Step 5:** Review “Appendix 8E: Adherence Assessment Guides” with participants and discuss how to conduct a readiness assessment. Note that there are 2 guides — one for adolescent clients and the other for caregivers.

Ask participants:

- *Why might it be important to ask adolescent clients and caregivers about adherence separately?*
- *How could these assessments be modified for young versus older adolescents?*
- *How do you think you could use these tools in your work/clinic?*



### **Make These Points**

- Assessing adherence and providing adherence support to clients and caregivers are important tasks, but can be challenging. There is no one particular way of assessing adherence. The best way is to use many a number of methods, such as a standardised adherence assessment combined with patient/caregiver self-report, pill count, and review of clinical and laboratory records.
- It is important to conduct the adherence assessment in an individual counselling session, to increase the likelihood of getting accurate responses and to provide opportunity to offer individual support tailored that that adolescent’s adherence needs.

## **Assessing Adherence**

Assessing adherence is very challenging and there is no perfect way to do so. Only through ongoing, individual adherence assessment and counselling, coupled with other adherence measures and review of the client’s response to ART over time can we really learn about adherence. It is very important to assess adherence at each visit, but we must also take the next steps after assessment to offer clients ongoing, individual adherence support.

- The purpose of ongoing adherence monitoring and support is to encourage the client (or caregivers) to express challenges and to be open about any problems they may be facing so that the multidisciplinary team can provide them with ongoing support.
- Assess adherence at every visit. If the caregiver or treatment buddy is available, ask him or her about adherence as well. Adolescents and caregivers may have different reports and understanding of adherence, so it is important to conduct separate adherence assessment sessions with older adolescent clients and their caregivers. Where answers to parallel questions differ greatly, discuss the divergent responses when

client and caregiver are together to see if they can explain. When asking for an explanation of divergent responses, ensure the question is appropriate and non-accusatory, for example: *“Interestingly, in response to my question ‘How did the medicines make your child feel?’ you said that the medicine was responsible for daily headaches, but your mother responded that the medicine had no effect on how you feel. I am sure you’re both right, but maybe either of you can explain further how your responses can seem, on the surface, to be so different?”*

- Make adherence assessment and support a normal part of every clinic visit. Remember, adherence and psychosocial support need to be adapted to the needs of the adolescent as they age.
- Do not judge! Make clients feel comfortable, let them know that they will not be punished or judged if they openly discuss adherence challenges.
- Share that everyone has problems taking medicines the right way all the time.
- Build a trusting relationship and encourage clients to be completely honest with you about adherence. Remember: the job of a healthcare worker is to work WITH clients, not against them!
- Refer the client to a peer support group or link him or her to a Peer Educator
- Talk about clients’ adherence at multidisciplinary team meetings.
- Use tools to help assess and improve adherence, such as:
  - Pill counts
  - Review of clinical findings and laboratory tests
  - Reviewing medicine diaries or calendars with clients

**Adherence Red Flag**

Missing pharmacy refills or clinic appointments is a RED FLAG to poor adherence and should be addressed immediately in any client on ART.

Routine adherence assessments help identify and solve specific adherence challenges in a timely manner. “Appendix 8E: Adherence Assessment Guides” includes two standardised adherence assessment tools which can be used at every follow up and refill visit to ensure that the adolescent client (and caregiver) understands the care and medication plan. The assessment questions should be used to identify areas where the client and/or caregiver may need additional information and support.

**How to ask clients (and caregivers) about their adherence:**

- *I would like you to think about the last 7 days. How many pills did you take late in the last 7 days? What were the main reasons you took them late?*
- *How many pills did you miss in the last 7 days? What were the main reasons you missed them?*
- *How did the medications make you feel?*
- *Can you tell me about any changes you noticed (such as in your health) lately?*
- *Can you tell me about any challenges you had with your medicines lately?*

- *What support or reminders do you have to take your medicines at the same time, every day?*
- *What questions do you have about your care or your medicines?*



### **Trainer Instructions**

Slides 58-61

**Step 6:** Discuss why it is important to provide ongoing adherence counselling and support to clients and caregivers. Ask the following questions to facilitate discussion:

- *Why is it important to provide ongoing adherence support?*
- *How do you think we can support long-term adherence to care among younger adolescents? Older adolescents? Caregivers?*

**Step 7:** Discuss what healthcare workers should do when a client reports good adherence to the care and treatment plan, and what they can do to help clients that may have adherence challenges.



### **Make These Points**

- Healthcare workers can PREVENT adherence problems through individual counselling and support to overcome barriers to adherence.
- Ongoing adherence support is especially important for adolescents. This is because their adherence to care and medications will not be static — meaning it changes over time — especially for ALHIV who are going through different phases of life and different life situations
- Peer education and support groups are valuable tools that can help adolescent clients with their adherence.
- Adherence support services should be ongoing — not one-time events — and the entire multidisciplinary team, not just counsellors or Peer Educators, is responsible for providing these services.

## **Providing Ongoing Adherence Support**

When providing adherence support, it is important that healthcare workers build on their trust and rapport with the client and caregiver, maintain a safe space to discuss any problems, and give ongoing encouragement and motivation. If, after discussing adherence with clients, the healthcare workers feels they are adhering well:

- Praise them (and the caregiver, if present) for good adherence.
- Remind them to come back if there are any problems.

- Talk about how important it is to be open with providers and healthcare workers and to solve challenges together.

If the healthcare worker or multidisciplinary team has determined that an adolescent client is experiencing challenges with adherence, provide individual counselling. During individual counselling:

- Praise the client for sharing his or her challenges.
- Identify the specific challenges and how these challenges affect adherence.
- Help resolve each of the challenges.
- Discuss the importance of adherence.
- Refer to the Peer Educator, adolescent support groups and other organisations.
- Refer difficult cases to a counsellor, social worker or other available mental healthcare worker.
- Plan for next steps, including the clinic return date.
- Record the session on the patient record.
- Follow up at the next visit.
- Share this with the multidisciplinary team and review the client’s clinical status to determine if poor adherence is impacting treatment outcomes.



### Trainer Instructions

Slides 62-67

#### Step 8:

Lead participants through Exercise 2, which gives an opportunity to practise how to conduct an adherence assessment with clients and caregivers and provide adolescent clients of different ages and their caregivers with ongoing adherence support.

### Exercise 2: Assessing Adherence and Providing Support: Role play and large group discussion

<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To practise conducting an adherence assessment with adolescent clients and caregivers, and providing ongoing adherence support.</li> </ul>
<b>Duration</b>	50 minutes
<b>Advance Preparation</b>	<ul style="list-style-type: none"> <li>• Review the case studies, and adapt if needed.</li> <li>• Be prepared to adequately explain how to complete the adherence assessment tool in “Appendix 8E: Adherence Assessment Guides”.</li> </ul>
<b>Introduction</b>	Explain that in this activity we are going to practise conducting an adherence assessment with adolescent clients and caregivers and providing adherence support and counselling to adolescents and caregivers.
<b>Activities</b>	<b>Part 1: Small Group Work</b>

	<ol style="list-style-type: none"> <li>1. Break participants into 4 small groups and assign each a case study. Also ask participants to refer to “Appendix 8E: Adherence Assessment Guides”.</li> <li>2. Ask each of the small groups to identify a “healthcare worker”, “client”, and “caregiver”.</li> <li>3. Assign each of the 4 “clients” and “caregivers” (in the 4 small groups) one of the case studies. Note that the first bullet point is shared with the “healthcare worker” the remaining bullet points are for the “client” and “caregiver”. The “clients” and “caregivers” should feel free to act and respond to the “healthcare worker” as they think their character might behave. Encourage “clients” and “caregivers” to use their imagination and make the part their own.</li> <li>4. The “healthcare workers” should not look at the case studies!</li> <li>5. Ask each of the groups to role play their case study. The “clients” should introduce themselves to the “healthcare workers” by reading aloud the 1<sup>st</sup> bullet point in their case studies. They should NOT read aloud the 2<sup>nd</sup> or 3<sup>rd</sup> bullet points!!! After the introduction the “healthcare workers” should go ahead and take the lead.</li> <li>6. The “healthcare workers” should provide adherence counselling and support as discussed in this session, ensuring that they use the adherence assessment in “Appendix 8E: Adherence Assessment Guides”. Depending on the case study the “healthcare worker” might want to meet with both the “client” and “caregiver”, then with the “client” and “caregiver” individually. Finally, the “healthcare worker” might want to meet with both to resolve any important differences of opinion, summarise key points and note the way forward.</li> <li>7. Participants who do not have roles may advise those who are role playing. Actors and non-actors may switch places during the role play.</li> <li>8. During the role plays, circulate between the groups to answer questions and to ensure they are conducting the counselling sessions as expected (see “Key points for trainers” below).</li> <li>9. After the role play, ask participants in each group to answer the following questions: <ol style="list-style-type: none"> <li>a. <i>What are the client’s/caregiver’s main adherence challenges? What are some possible solutions?</i></li> <li>b. <i>What are some age-appropriate techniques and/or approaches a healthcare worker could use to build the client’s/caregiver’s confidence and knowledge about adherence?</i></li> <li>c. <i>Are there any community outreach/services that might</i></li> </ol> </li> </ol>
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	<p><i>help the client? What suggestions or referrals would you make?</i></p> <div style="border: 1px solid black; padding: 5px; margin: 10px 0;"> <p>Note to trainers: the “Key points for trainers” (below) do not specifically address these 3 questions, as the answers depend on how the role play proceeds. Instead, the “Key points for trainers” focus on process — how the “healthcare worker” could conduct the adherence support session to get the answers to the above questions.</p> </div> <p><b>Part 2: Large Group Discussion</b></p> <p>10. Bring participants back to the large group. Have each small group summarise their case study and the answers to the 3 questions (above). Compare the process that the groups went through with the “Key points for trainers” below.</p> <p>11. After all 4 groups have reported, ask the following questions to facilitate discussion and record key points on a flip chart:</p> <ul style="list-style-type: none"> <li>• <i>What do you think will be the most challenging aspects of conducting and adherence assessments with ALHIV and their caregivers in your clinic?</i></li> <li>• <i>What do you think are the most important features of your communication/counselling approach, to ensure you get honest answers from your clients?</i></li> </ul> <p>12. (optional) Encourage participation from the adolescent co-trainer, who should also participate in the small groups and role plays. Ask the following questions to encourage his or her input and participation:</p> <ul style="list-style-type: none"> <li>• <i>Is there anything else the healthcare worker could suggest or discuss to address the client’s adherence needs?</i></li> </ul>
<b>Debriefing</b>	<ul style="list-style-type: none"> <li>• An adolescent client’s adherence needs change over time and as they age and develop, and should be assessed and considered at every visit.</li> <li>• Often it is helpful to ask clients and caregivers about adherence separately, as there may be different understanding and answers.</li> <li>• It is important that healthcare workers build a trusting relationship with adolescent clients so that they feel comfortable being completely honest about their adherence support needs.</li> <li>• It is important not to judge clients (and caregivers) if they are non-adherent. Instead, we should try to understand why clients do not adhere and help clients and caregivers find ways to resume good adherence as soon as possible.</li> </ul>

## Exercise 2: Assessing Adherence and Providing Support: Role play and large group discussion

### Case Study 1: Jonathon

- **At beginning of role play, “Client” (Jonathon) introduces himself to the “healthcare worker”:** I am Jonathon, I am 17 years old and have perinatally acquired HIV. My parents died many years ago, I live with my uncle and his family. My uncle came with me today.
- **When asked by the “healthcare worker”:** Uncle (the “Caregiver”) says that Jonathon is often out all night and comes home drunk. The family is upset with his behaviour and is afraid for him. The uncle says that Jonathon used to be a good student and did well in school. Recently he has not been taking his ARVs regularly, maybe he hasn’t taken his ARVs at all. Uncle is angry with his nephew and says that he found medication thrown away in the outhouse. He wants the healthcare worker to frighten Jonathon into taking his medication. Uncle discloses that he also has HIV.
- **When asked by the “healthcare worker”:** Jonathon states that he thinks that he has taken about half of his ART doses over the past week, mostly because he’s just been too busy.

### Key points for trainers: Jonathon and Uncle

- During the **individual session with Uncle**, the “healthcare worker” should:
  - Administer the “Adherence Assessment for Caregivers of Adolescents Taking ART”.
  - Tell Uncle that frightening, although one way to motivate, is rarely the most effective. Instead, the “healthcare worker” should let him know that he or she will try other ways to encourage Jonathon to adhere to his regimen (discuss barriers, address barriers, educate, motivate, etc).
- During the **individual session with Jonathon**, the “healthcare worker” should:
  - Administer the “Adherence Assessment for Adolescents Taking ART”.
  - Use listening and learning skills to uncover the answer to **question “a”**. During the discussion identify Jonathon’s strengths, and praise him to build confidence — **question “b”**.
  - Ask — in a non-confrontational manner — Jonathon about the suggestion that he’s often out all night: *“Jonathon, I understand that sometimes you stay out quite late, can you tell me your side of the story?”* This may open the discussion around some of the underlying reasons for his poor adherence — his irregular hours and excessive drinking.
  - Keep in mind Uncle’s side of the story as Jonathon responds to the questions about his adherence. If the stories differ, the

“healthcare worker” might want to mention (if he feels he will not be breaching Uncle’s confidentiality), for example: *“Your Uncle worries about you because he loves you, he thinks that you might have thrown out your medicine, is that correct?”*

- Educate Jonathon around the importance of adherence and the risks he takes by not adhering to his regimen (this will build knowledge, and responds to **question “b”**).
- Find out what motivate Jonathon: What is important to Jonathon? Is it marriage and family, future career, or maybe he just wants to look good? Reassure Jonathon that ART can help him to achieve his life’s goals. (this will build confidence, and responds to **question “b”**)
- If Jonathon states that he loves or respects his Uncle’s family, the “healthcare worker” may also mention that *“Did you know that not taking care of yourself has been upsetting the people who love you?”*
- After the healthcare worker meets with Jonathon and Uncle separately, he or she might want to meet with them together to try to summarise the way forward, discuss next steps, and provide referrals (**question “c”**) to a Peer Educator, peer support group, and any other appropriate referrals (substance abuse counselling?). Jonathon It is during the meeting with both the client and caregiver that the “healthcare worker” can typically bring up some of the differing perspectives, but in this case, it might be too volatile.
- Discussion questions for this case study: Ask the small group:
  - *During the individual counselling session with Jonathon, how well did the “healthcare worker” do in getting the truth out of Jonathon?*
  - *What did the “healthcare worker” do to “marry up” the 2 divergent stories (one from Jonathon and the other from Uncle)?*
  - *Was the “healthcare worker” able to do this without alienating either of them?*

### **Case Study 2: Nicholas**

- **At beginning of role play, “Client” (Nicholas) introduces himself to the “healthcare worker”:** I am Nicholas, I am 12 years old and have and have been on ART for the last 6 years. My mother is here with me.
- **When asked by the “healthcare worker”:** **Mother** (the “Caregiver”) complains that Nicholas always used to cooperate and take his medicines with no problem. But now he is fighting her with every dose, runs away, and spits out his ARVs. Although Mother is planning to tell Nicholas his diagnosis, she actually has not used the term “HIV” just yet.
- **When asked by the “healthcare worker”:** **Nicholas** states that his mother forces him to take his medicine every morning and every evening. But he does not want to take them anymore because he just wants to be normal and not take medicine, his friends do not take medicine, so why does he have to?

### Key points for trainers: Nicholas and Mother

- During the **individual session with Mother**, the “healthcare worker” should:
  - Administer the “Adherence Assessment for Caregivers of Adolescents Taking ART”.
  - Get a feel for Mother’s communication style, ask her why she thinks Nicholas is suddenly non-cooperative when it comes to taking his medicine. What has changed recently for Nicholas? What techniques has she used to encourage Nicholas to take his medicines? Does Nicholas have any new friends? Has anyone made fun of him for taking medications?
  - Ask if Nicholas knows his HIV status (disclosure)? If not, could knowing his HIV status help?
- During the **individual session with Nicholas**, the “healthcare worker” should:
  - Administer the “Adherence Assessment for Adolescents Taking ART”.
  - Use listening and learning skills to uncover the answer to **question “a”** and better understand what has happened over the past few months to explain why he doesn’t want to take his medicines any longer. During the discussion identify Nicholas’ strengths, and praise him to build confidence — **question “b”**.
  - Ask what he knows about why he takes his medicine.
  - Educate Nicholas around the importance of adherence and the risks he takes by not adhering to his regimen. Ensure this discussion is worded in a way that is respectful to Nicholas’ understanding of his diagnosis (this conversation will build knowledge, and responds to **question “b”**).
  - Find out what motivate Nicholas: What is important to Nicholas? What does he want to be when he grows up? What’s important to him now? Reassure Nicolas that ART can help him to achieve his life’s goals (this will build confidence, and responds to **question “b”**).
- After the healthcare worker meets with Nicholas and Mother separately, he or she might want to meet with them together to try to “marry up” any differences of opinion (if there were any), discuss the plan as agreed with Nicholas, summarise next steps, and provide referrals (**question “c”**) to a Peer Educator and peer support group
- Discussion questions for this case study: Ask the small group:
  - *Did the issue of disclosure come up in your counselling session with either Nicholas or Mother?*

### Case Study 3: Mana

- **At beginning of role play, “Client” (Mana) introduces herself to the “healthcare worker”:** I am Mana, a 14-year-old female. I’ve come in

today because I am feeling bad and I want to stop taking ART. I am here today with my best friend.

- **When asked by the “healthcare worker”:** Mana states that she’s missed 3 doses of her ART in the last month but thinks that taking the doses most of the time is good enough. She tells you that she thinks the pills are making her look fat and she feels self-conscious about her body. She also tells you that she really likes this boy in her class but is afraid he thinks she is ugly. She says she is teased when she goes to school and only has one friend (the girl who accompanied her today).

#### **Key points for trainers: Mana**

- Note: as Mana has brought a girlfriend with her (rather than a caregiver), there’s unlikely to be any compelling reason for the “healthcare worker” to meet individually with this girlfriend.
- During the **individual session with Mana**, the “healthcare worker” should:
  - Administer the “Adherence Assessment for Adolescents Taking ART”.
  - Use listening and learning skills to uncover the answer to **question “a”** (which we know has more to do with body image and poor self-esteem, rather than actually feeling unwell).
  - Use listening and learning skills to address Mana’s key issue right now: low self-esteem. Praise her for what she has done well (for example, missing 3 out of 60 ART doses in the last month isn’t bad, it equates to a 95% adherence rate). Encourage her to try new activities at school to build self confidence and meet new people — **question “b”**.
  - Educate Mana around the importance of adherence and the risks she takes by not adhering to her regimen. Let her know that if she stops taking ART, she will loose weight and eventually start to look sickly (which is surely, less appealing than looking a bit fat, correct?). This conversation builds knowledge — **question “b”**.
  - Discuss exercise as a way to burn off excess weight, feel better about body image and build self confidence (again, informing **question “b”**).
  - Find out what motivates Mana: What is important to Mana? What does she want to be when she grows up? What’s important to her now? Reassure Mana that ART can help her to achieve her life’s goals (this should build confidence, and responds to **question “b”**).
  - Provide referrals (**question “c”**) to a Peer Educator and peer support group.
  - Ask Mana if she would like to include her girlfriend in the rest of the conversation. This will give the girlfriend an opportunity to ask any questions she may have. The “healthcare worker” can also empower the girlfriend with information on the importance of adherence, so that she can support Mana’s decision to not go off

ART. The girlfriend can also support Mana to exercise more, try new things.

- Discussion questions for this case study: Ask the small group:
  - *Did you include Mana's girlfriend in any way? How could she be used?*

#### **Case Study 4: Mary**

- **At beginning of role play, “Client” (Mary) introduces herself to the “healthcare worker”:** I am Mary, I am 16 years old and have come in today for my routine visit. As always, my mother is here with me. The doctor told me to give this to you (Mary should hand over her pretend medical record with the results of her last 2 CD4 tests — which show a decrease in her CD4 count).
- **When asked by the “healthcare worker”:** **Mother** (the “Caregiver”) reports that Mary has taken 100% of her medicines on time this month.
- **When asked by the “healthcare worker”:** **Mary** states that she has taken 100% of her medicines on time this month.

#### **Key points for trainers: Mary and Mother**

- During the **individual session with Mother**, the “healthcare worker” should:
  - Administer the “Adherence Assessment for Caregivers of Adolescents Taking ART”.
  - Praise her daughter for her excellent adherence and ask how it is that Mary can remember every single time.
  - Inform Mother that the laboratory test results suggest that Mary’s health is declining. Can Mother help to explain this? Is it possible that she’s not taking all of her medicines as directed?
  - Try to validate the report of 100% adherence with pill counts and pharmacy refill records (if available)
  - Let Mother know that it’s OK to be honest, we’re here to help, not judge.
- During the **individual session with Mary**, the “healthcare worker” should:
  - Administer the “Adherence Assessment for Adolescents Taking ART”.
  - Praise Mary for what appears to be perfect adherence, this builds confidence — **question “b”**.
  - Present her with the result of the pill counts and check on pharmacy refill records (if available).
  - Inform Mary that the laboratory test results suggest that her health is declining. Can she explain this? Use listening and learning skills to find out if it is possible that she’s not taking all of her medicines as directed (getting at the answer to **question “a”**).
  - Let Mary know that it is OK to be honest, we are here to help, not judge. Discuss the importance of excellent adherence and the

risks one takes by not adhering to their regimen (this conversation will build knowledge, and responds to **question “b”**).

- Ask Mary about anything he or she learned during the individual session with Mother that needs validation.
- Ask Mary about sexual partners, discuss safer sex, note that one of the risks of unsafe sex is that you can acquire a new strain of HIV that is resistant to your medications. Is this a possibility for her?
- After the healthcare worker meets with Mary and Mother separately, he or she might want to meet with them together to try to “marry up” any differences of opinion (if there were any), discuss the plan as agreed with Mary, summarise next steps, and provide referrals (**question “c”**) to a Peer Educator and peer support group.
- Discussion questions for this case study: Ask the small group:
  - *Was Mary really taking 100% of her medicines?*



#### **Trainer Instructions**

**Step 9:** Allow 5 minutes for questions and answers on this session.



#### **Trainer Instructions**

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**Step 10:** Ask participants what they think the key points of the module are. What information will they take away from this module?

**Step 11:** Summarise the key points of the module using participant feedback and the content below.

**Step 12:** Ask if there are any questions or clarifications.



## Module 8: Key Points

- Retention refers to keeping (or “retaining”) clients in the care programme, in this case continuing with lifelong HIV care and treatment services. For adolescents, this also means transitioning them to adult care and treatment.
- In the context of ART, studies have shown that clients must take over 95% of the necessary doses to achieve the conditions for therapeutic success, i.e. clients should adhere or “stick” to at least 95% of their drug schedule. Therefore, as healthcare workers our aim is to support clients to achieve and sustain this rate of adherence to their regimens.
- Although it is ultimately the responsibility of clients to adhere to their care plans, there are many steps healthcare workers can take to make it easier for clients to adhere to care. One of the most important steps to improve retention in care is to ensure that services are youth friendly. Services that are youth friendly increase the likelihood of attendance and therefore the likelihood of perfect, or near-perfect adherence to treatment.
- The Zambia “Adult and Adolescent Antiretroviral Therapy Protocols, 2010” recommend a minimum of 3 adherence preparation visits, as part of a structured treatment preparation plan prior to initiating ART.
- In addition, the healthcare worker can help the client to develop a personal adherence plan by:
  - Asking the ARE YOU COMMITTED and then the WHO, WHAT, WHEN, WHERE and HOW of the medications.
  - Administering a standardised assessment tool to help determine a client and caregiver’s readiness for ART and help them to form an adherence plan.
- Assessing adherence and providing adherence support to clients and caregivers are important tasks, but can be challenging. There is no one particular way of assessing adherence. The best way is to use many a number of methods, such as a standardised adherence assessment combined with patient/caregiver self-report, pill count and review of clinical and laboratory records.
- Adherence support services should be ongoing — not one-time events — and the entire multidisciplinary team, not just counsellors or Peer Educators, is responsible for providing these services.
- Ongoing adherence support is especially important for adolescents. This is because their adherence to care and medications will not be static — meaning it changes over time — especially for ALHIV who are going through different phases of life and different life situations.

## Appendix 8A: Key Points — Adherence Preparation Visit 1

### Checklist for adherence preparation visit 1

✓	Topic and key points
	<b>1. What is HIV?</b>
	<ul style="list-style-type: none"> <li>• HIV is a virus that attacks the body</li> <li>• It damages your ability to fight germs and disease</li> <li>• The virus makes many copies of itself every day if you are not on treatment</li> <li>• Without treatment people progress from no symptoms to minor illness to severe life threatening illness and death</li> </ul>
	<b>2. What is AIDS?</b>
	<ul style="list-style-type: none"> <li>• AIDS occurs when the body is overcome by the HIV virus and becomes weak due to other illnesses</li> <li>• HIV causes AIDS months to years after infection</li> </ul>
	<b>3. How is HIV spread?</b>
	<ul style="list-style-type: none"> <li>• Unprotected sex is the most common method</li> <li>• Sharing needles or blood contaminated sharp objects (razors, knives, etc)</li> <li>• Mother-to-child either before, during or after delivery (in the womb, during delivery, or while breastfeeding)</li> <li>• Infected body fluids in contact with:               <ul style="list-style-type: none"> <li>• Soft moist skin in the mouth, nose, vagina or rectum</li> <li>• Cuts in the skin</li> </ul> </li> <li>• Traditional beliefs that facilitate HIV transmission (sexual cleansing, wet nursing, dry sex, pre-coital pubic shaving with shared razor, etc)</li> <li>• HIV is NOT spread through sharing food or utensils, touching, kissing, mosquitoes, or curses</li> </ul>
	<b>4. How can HIV be prevented?</b>
	<ul style="list-style-type: none"> <li>• Abstaining from sex</li> <li>• Knowledge of sexual partner's HIV status</li> <li>• Being faithful to one partner/spouse</li> <li>• Using condoms when engaging in sexual contact</li> <li>• Becoming circumcised if an HIV negative male</li> <li>• Taking ARVs perfectly or near-perfectly (discuss how they can prevent re-infecting themselves or infecting others)</li> </ul>
	<b>5. Which of your partners or family members need to be referred for HIV testing? Review how a person gets tested for HIV.</b>
	<ul style="list-style-type: none"> <li>• A simple blood test</li> <li>• HIV test may not be positive for up to 3–6 months after infection (window period)</li> <li>• Retest every 3–6 months if you are at risk</li> </ul>

	<ul style="list-style-type: none"> <li>The standard test looks for an immune system reaction to HIV</li> </ul>
<b>6. Who will you tell that you have HIV? It is important to disclose your status to someone you trust and notify your sexual partner.</b>	
	<ul style="list-style-type: none"> <li>Sharing your test results with someone you trust who can support you is associated with better success in managing HIV</li> </ul>
	<ul style="list-style-type: none"> <li>Your family should become a source of support and help in your HIV care and treatment</li> </ul>
	<ul style="list-style-type: none"> <li>Notifying your sexual partners so they can be tested also can help stop HIV spreading. If any of your partners are HIV infected, they can seek early care.</li> </ul>
<b>7. What is the meaning of CD4 cells?</b>	
	<ul style="list-style-type: none"> <li>The immune system works in your body to fight infections and keep you healthy</li> </ul>
	<ul style="list-style-type: none"> <li>CD4 cells are the “soldiers” of your immune system army</li> </ul>
	<ul style="list-style-type: none"> <li>CD4 cells recognise germs in your body, and they work with other cells to destroy them</li> </ul>
	<ul style="list-style-type: none"> <li>HIV attacks and destroys your CD4 cells</li> </ul>
	<ul style="list-style-type: none"> <li>When CD4 cells are destroyed by HIV, the immune system does not know how to fight germs</li> </ul>
<b>8. What is viral load?</b>	
	<ul style="list-style-type: none"> <li>Viral load is the amount of HIV virus in the blood</li> </ul>
	<ul style="list-style-type: none"> <li>The lower the amount of HIV virus in the blood the better</li> </ul>
	<ul style="list-style-type: none"> <li>When the amount of HIV virus increases, eventually you don’t have enough CD4 cells to fight HIV and other germs that enter your body, and you progress to AIDS. You want to have more CD4 cells in your body and little HIV virus in your body</li> </ul>
<b>9. What is cotrimoxazole (also referred to as “CTX”)?</b>	
	<ul style="list-style-type: none"> <li>CTX can help prevent illnesses before you start HIV treatment. Taking CTX everyday can help your body fight off germs that can cause pneumonia, diarrhoea, toxoplasmosis and malaria</li> </ul>
	<ul style="list-style-type: none"> <li>Your healthcare worker will tell you if you should be taking CTX</li> </ul>
	<ul style="list-style-type: none"> <li>Taking CTX before HIV treatment is good practice for adhering to HIV treatment</li> </ul>
<b>10. What are the benefits of starting HIV treatment (also known as antiretroviral therapy or “ART”)?</b>	
	<ul style="list-style-type: none"> <li>Starting HIV treatment before you become sick and have AIDS will make it easier to lower the HIV virus in your blood and increase your CD4 cells faster</li> </ul>
	<ul style="list-style-type: none"> <li>It will also make the potential side effects from treatment easier to tolerate</li> </ul>
	<ul style="list-style-type: none"> <li>It will prevent you from developing more serious infections, and improve your chance of living a normal life with HIV</li> </ul>
<b>Summary of visit 1</b>	
	<ul style="list-style-type: none"> <li>HIV is a disease of the immune system: <ul style="list-style-type: none"> <li>HIV is a virus that infects blood</li> <li>HIV is passed from one person to another through blood or</li> </ul> </li> </ul>

	<p>certain body fluids</p> <ul style="list-style-type: none"><li>• HIV reproduces very fast and attacks and kills CD4 cells</li><li>• CD4 cells are needed to fight HIV and other germs</li><li>• Viral load measures how much HIV is in your blood and predicts how well you will do</li><li>• CD4 cells measure how well your immune system fights germs</li><li>• Disclosing your results to someone you trust is very important</li><li>• Your examination and laboratory results will help determine whether you need treatment now:</li><li>• Soft moist skin in the mouth, nose, vagina or rectum</li></ul>
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**Source:**

Government of the Republic Of Zambia, Ministry Of Health. 2010. *Adult and Adolescent Antiretroviral Therapy Protocols 2010*.

## Appendix 8B: Key Points — Adherence Preparation Visit 2

### Checklist for adherence preparation visit 2

✓	Topic and key points
	<b>1. What is ARV?</b>
	<ul style="list-style-type: none"> <li>• ARV stands for <b>Anti-Retro Viral</b></li> <li>• ARVs are medicines that help control the HIV virus in the blood</li> <li>• ART is <b>Anti-Retroviral Therapy</b>, and refers to the combination of ARVs that are used to fight HIV</li> </ul>
	<b>2. Who should start ART?</b>
	<ul style="list-style-type: none"> <li>• You cannot always tell by looking at someone if they need ART</li> <li>• Even if you look and feel healthy, your immune system may already be weakened (low CD4 cell count), and you may benefit from starting ART to prevent you from getting sick</li> <li>• You should start ART if you are experiencing illnesses or your immune system is weakened (low CD4 cell count)</li> <li>• An HIV-positive person does not always need to start ART immediately, and some people may have no illnesses and a healthy immune system (high CD4 cell count) and can delay ART, but should remain in care with regular follow up</li> </ul>
	<b>3. What are the other considerations before starting ART?</b>
	<ul style="list-style-type: none"> <li>• Several considerations are associated with success when starting ART               <ul style="list-style-type: none"> <li>• Disclosing your status to someone that you trust is associated with better success on ART</li> <li>• Identifying a treatment supporter or buddy that can help you with ART is very important</li> <li>• Identifying linkages to the community through home based care, treatment support groups, and other community services will help you be more successful with your treatment</li> <li>• Discuss fears and questions with your health care team members</li> <li>• Always keeping a supply of medication with you and NEVER running out</li> <li>• Heavy drinking of alcohol and depression can lower your adherence and reduce your success when taking ART</li> </ul> </li> <li>• Medication issues that will be discussed in visit 3</li> </ul>
	<b>4. Starting ART is never an emergency</b>
	<ul style="list-style-type: none"> <li>• Starting ART is an individual decision and one that is not forced</li> <li>• Those who are already sick with AIDS will need ART, however <b>STARTING ART IS NEVER AN EMERGENCY</b></li> <li>• Opportunistic Infections and other illnesses should be identified and treated before starting ART</li> <li>• ARVs may cause side effects, however most people tolerate ART</li> </ul>

	well, and specific potential side effects will be discussed prior to starting ART
	<b>5. What are the benefits of starting ART?</b>
	<ul style="list-style-type: none"> <li>• ART increases the CD4 cell count</li> </ul>
	<ul style="list-style-type: none"> <li>• ART allows the body to better fight infections by restoring the immune system</li> </ul>
	<ul style="list-style-type: none"> <li>• A healthy immune system will lead to fewer hospitalisings</li> </ul>
	<ul style="list-style-type: none"> <li>• ART can allow you to live longer so that you can marry and start a family if that is what you want</li> </ul>
	<ul style="list-style-type: none"> <li>• ART can help you gain weight, feel more energetic, and improve your sexuality</li> </ul>
	<ul style="list-style-type: none"> <li>• ART can decrease the risk of transmitting HIV to others</li> </ul>
	<b>6. What are the benefits of delaying ART?</b>
	<ul style="list-style-type: none"> <li>• You have more time to prepare yourself to be successful with ART</li> </ul>
	<ul style="list-style-type: none"> <li>• You don't have to take medication or risk experiencing side effects</li> </ul>
	<b>7. What is resistance?</b>
	<ul style="list-style-type: none"> <li>• Resistance is when the HIV virus changes itself and the ARVs can no longer work</li> </ul>
	<b>8. How does resistance occur?</b>
	<ul style="list-style-type: none"> <li>• Resistance can occur when you miss doses of your medicine or take them incorrectly. HIV virus uses this chance to make more and more copies of itself that are so different that your medicines stop working</li> </ul>
	<ul style="list-style-type: none"> <li>• Resistance can also occur if you get infected with an HIV virus that is already resistant to the medications that you are taking, or if you get re-infected with an type of HIV virus that is already resistant to the medications that you are taking (always practise safe sex to avoid infection or re-infection)</li> </ul>
	<b>9. How do you prevent resistance?</b>
	<ul style="list-style-type: none"> <li>• You can prevent resistance through excellent adherence</li> </ul>
	<ul style="list-style-type: none"> <li>• Excellent adherence requires that you take your medicines every day at the right time and in the right way (dose and combination)</li> </ul>
	<ul style="list-style-type: none"> <li>• It also means always collecting your medicines on time so that you never run out of ART, and making sure that you take them when travelling away from home (funerals, holidays, other emergencies) or while away at work (miners, truck drivers, etc)</li> </ul>
	<b>10. Why is excellent adherence necessary?</b>
	<ul style="list-style-type: none"> <li>• The best way to live a long life with HIV is too keep the first ART combination working as long as possible</li> </ul>
	<ul style="list-style-type: none"> <li>• When ART is not taken properly the virus can change (viral mutation) and then the medicines quit working and resistance has developed</li> </ul>
	<ul style="list-style-type: none"> <li>• Once resistance occurs, it is NOT reversible and will last forever</li> </ul>
	<ul style="list-style-type: none"> <li>• When resistance develops you are no longer able to fight the HIV</li> </ul>

	in your body and you risk getting sick and dying
	<ul style="list-style-type: none"> <li>• It will then become necessary to find a different combination of ART medicines to treat your HIV virus. The second ART combination may not work as well as the first ART combination and it may have more side effects, and is very expensive</li> </ul>
	<ul style="list-style-type: none"> <li>• Without excellent adherence eventually you run the risk of having no treatment options for HIV</li> </ul>
	<b>Summary of visit 2</b>
	<ul style="list-style-type: none"> <li>• ART are medicines that help control the HIV in the blood <ul style="list-style-type: none"> <li>• Starting ART is never an emergency</li> <li>• Not all HIV-positive persons need to start ART immediately</li> <li>• Consider medical and social factors before starting ART</li> <li>• ART helps the immune system get healthy (higher CD4 cell count)</li> <li>• Resistance is when the HIV virus changes itself and ART can no longer work</li> <li>• ART requires excellent adherence for life</li> </ul> </li> </ul>

**Source:**

Government of the Republic Of Zambia, Ministry Of Health. 2010. *Adult and Adolescent Antiretroviral Therapy Protocols 2010*.

## Appendix 8C: Key Points — Adherence Preparation Visit 3

### Checklist for adherence preparation visit 3

✓	Topic and key points
	<b>1. Can resistant virus be transmitted from one person to another?</b>
	<ul style="list-style-type: none"> <li>• A resistant virus can be transmitted to another person through sex and other high risk exposures</li> </ul>
	<ul style="list-style-type: none"> <li>• Someone who is not taking their ARVs correctly and develops resistant virus can pass the virus to:               <ul style="list-style-type: none"> <li>• An uninfected person (then they will start their HIV infection with virus that is already resistant to ART)</li> <li>• An infected person who is taking their ARVs correctly, and then develops resistance to the new resistant HIV virus that was passed on to them</li> </ul> </li> </ul>
	<ul style="list-style-type: none"> <li>• Practise safe sex even if you and your partner are both HIV-positive to avoid passing on resistant virus</li> </ul>
	<b>2. How can resistance be prevented?</b>
	<ul style="list-style-type: none"> <li>• Resistance can be prevented by excellent adherence</li> </ul>
	<ul style="list-style-type: none"> <li>• Partial adherence puts your virus at risk for resistance</li> </ul>
	<ul style="list-style-type: none"> <li>• Excellent adherence requires a person to take their ART medicines every day at the right time and in the right way, and NEVER run out of medication</li> </ul>
	<b>3. Can I feel resistance when it happens?</b>
	<ul style="list-style-type: none"> <li>• Resistance is like a silent side effect and you will not feel any different at first when your HIV virus becomes resistant to your ART</li> </ul>
	<ul style="list-style-type: none"> <li>• Resistance will make your ART become less effective, and eventually the number of HIV viruses in your blood increases then your CD4 cells decrease and eventually you will get sick and feel worse</li> </ul>
	<b>4. How can I ensure the success of my treatment plan?</b>
	<ul style="list-style-type: none"> <li>• Keep all scheduled appointments and pharmacy refills</li> </ul>
	<ul style="list-style-type: none"> <li>• Make sure the health facility knows how to contact you and your buddy (up to date phone numbers and address) and contact your health care facility or healthcare worker for any problems with medications (side effects, lost medicine, unable to make appointment, etc) or new illnesses</li> </ul>
	<ul style="list-style-type: none"> <li>• Use a defined schedule for taking your ARVs and use helps such as calendars, pill boxes, checklist to ensure that doses are not missed</li> </ul>
	<ul style="list-style-type: none"> <li>• Involve family members or a treatment supporter (buddy) in your care and keep them up to date with your progress</li> </ul>
	<ul style="list-style-type: none"> <li>• Stay healthy with good nutrition and exercise</li> </ul>

	<ul style="list-style-type: none"> <li>Plan for emergencies before they happen (rainy season, floods, funerals, holidays, lost medicine) so that you do not run out of medication</li> </ul>
	<ul style="list-style-type: none"> <li>Do not STOP your medicines without discussing with a healthcare worker</li> </ul>
	<ul style="list-style-type: none"> <li>Do not take other herbal or over the counter medicines without discussing with your healthcare worker</li> </ul>
	<b>5. Should I learn the names of my ART medications?</b>
	<ul style="list-style-type: none"> <li>Yes, you should remember the names of the medicines you take and how they are to be taken</li> </ul>
	<ul style="list-style-type: none"> <li>Know the potential side effects and what to do if they occur</li> </ul>
	<ul style="list-style-type: none"> <li>Know about potential drug interactions between your medicines</li> </ul>
	<b>Summary of visit 3</b>
	<ul style="list-style-type: none"> <li>Resistance is not reversible and compromises treatment success <ul style="list-style-type: none"> <li>Patients should not start ART if they cannot commit to excellent adherence</li> <li>Develop a successful treatment plan</li> <li>Review ART medication side effects</li> <li>Patients should understand the Patient Readiness Questionnaire and answer correctly</li> </ul> </li> </ul>

**Source:**

Government of the Republic Of Zambia, Ministry Of Health. 2010. *Adult and Adolescent Antiretroviral Therapy Protocols 2010*.

## Patient Readiness Questionnaire

Prior to dispensing, healthcare workers should review the Patient Readiness Questionnaire with the client to make sure he or she understands ART.

Question	Mark the correct answer	
1. ART can cure HIV/AIDS.	<input type="checkbox"/> True	<input type="checkbox"/> False
2. People taking ART should still abstain from sex or use condoms when having sex to be sure not to pass HIV to their sexual partners.	<input type="checkbox"/> True	<input type="checkbox"/> False
3. ART works well as long as at least half the doses are taken correctly.	<input type="checkbox"/> True	<input type="checkbox"/> False
4. What would you do if you think you are having a bad side effect from the ART?	a. Continue taking your ART and go to the clinic b. Stop the one that you think is making you feel bad, but continue the others c. Stop all the ART medicines and resume taking them when you feel better	
5. What is HIV resistance?	a. When you don't like your medicines b. When your body "resists" your medicines c. When the HIV virus changes in a way that stops your medicines from working to keep your HIV virus under control d. When your medicine changes in a way that stops them from keeping your HIV under control	
6. What can cause resistance?	a. When you forget to take your HIV medicines b. When the amount of medicine in your body is too low from missed doses c. When HIV makes copies of itself that are different from the original d. All of the above	
7. If my HIV virus develops resistance it will go away once I become adherent to my medications and I can continue with my current ART.	<input type="checkbox"/> True	<input type="checkbox"/> False
8. I can be re-infected with HIV that is already resistant to my ART.	<input type="checkbox"/> True	<input type="checkbox"/> False

<p>9. There is no cure for HIV. If I stop ART after someone says that I am cured (faith healing, herbal medicines, etc) the HIV will come back, and I may develop resistance and the ART will not work.</p>	<input type="checkbox"/> True	<input type="checkbox"/> False
<p>10. I agree to identify a treatment supporter or buddy, and allow home visits.</p>	<input type="checkbox"/> True	<input type="checkbox"/> False
<p>11. I understand that herbal medicines can work against ART.</p>	<input type="checkbox"/> True	<input type="checkbox"/> False
<p>12. I understand that ART, if taken correctly, will help prolong my life.</p>	<input type="checkbox"/> True	<input type="checkbox"/> False

**Source:**

Government of the Republic Of Zambia, Ministry Of Health. 2010. *Adult and Adolescent Antiretroviral Therapy Protocols 2010.*

## **Appendix 8D: Adherence Preparation and Support Guides**

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### **How to use these guides:**

These adherence preparation and support guides were developed to assist a range of providers (trained counsellors, lay counsellors, Peer Educators, doctors, nurses, pharmacists, community healthcare workers, and others) who work with adolescents living with HIV (ALHIV) and their caregivers. These guides can help providers work with their clients (and caregivers) to understand the importance of adherence to HIV care and treatment throughout their life; to ensure understanding of the care and medications plan; to identify potential adherence challenges; and to come up with practical solutions. The adherence guides should be adapted to reflect national HIV care and treatment guidelines, as well as the specific clinic, community, and cultural contexts in which they are used, including the age and situation of the individual adolescent client. It may be helpful to translate the guides into the local language.

Often, adherence preparation is not tailored to the specific needs and concerns of adolescents and, in some cases, adolescents are referred to adult ART clinics, which may not be youth-friendly, for adherence counselling and preparation. Many programmes stipulate that clients participate in a series of group and individual counselling and preparation sessions before starting ART.

Included is one adherence preparation and support guide to assess adolescents' readiness for ART and one to assess the readiness of caregivers. The forms should be adapted as needed and used during adherence counselling sessions, according to the client's (and caregiver's) needs and situation. Completed adherence assessment forms should be kept in the client's file and referred to during follow-up visits.

### **Basic information:**

Write the client's name and file number at the top of the form. Be sure to sign and date the form at the end of each session and ensure that the form is kept in the client's clinic file.

### **Questions to ask the client/caregiver:**

The questions in this section allow the healthcare worker to discuss specific care, medication, and adherence issues with the adolescent client/caregiver. The questions should be used to identify areas where the client/caregiver may need additional information and support, but should not be used to "score" a client's knowledge and readiness to take ARVs. It is important to allow time for the client/caregiver to respond to each question. Adolescent clients and caregivers should always be made to feel

comfortable asking questions and expressing potential adherence challenges and they should never be judged or punished. Remember to write down any important information from their responses, as this will help decide on next steps, important areas for follow up, and in supporting the client's adherence over the long term.

**Client/caregiver requires more counselling and support in these areas:**

Write down specific areas in which the adolescent client/caregiver needs ongoing adherence counselling and support. Refer to this section of the form during follow-up counselling appointments and clinic visits. Even if a client has questions about his or her care and medicines, or is facing specific adherence challenges, this is usually not a reason to delay initiation of ARVs/ART. Instead, these issues should be viewed as important areas for ongoing counselling and support.

## Adherence Preparation/Support Guide for Assessing Adolescents' Readiness for ART

**Client's Name:** \_\_\_\_\_ **Client's Age:** \_\_\_\_\_ **Client's File#:** \_\_\_\_\_  
**Caregiver and/or Treatment Buddy's Name:** \_\_\_\_\_

Questions to ask the adolescent client:	Notes
1. Can you tell me what peer support group or group education sessions you have attended here at the clinic?	
2. Can you explain why you need to take ARVs?	
3. Who have you spoken to/who knows about your HIV status?	
4. What do you expect from taking ARVs?	
5. How do you feel about taking medicines every day for your lifetime?	
6. Can you tell me the names of the ARVs you will be taking and when you will take them (how many pills, what times of day)?	
7. Can you tell me some possible side effects of your ARVs? What will you do if you have side effects?	
8. Can you explain what happens if you do not take all of your ARVs every day, at the same time?	
9. Who can help you come to the clinic for appointments and help you take your medicines every day? What is their name and contact information?	
9a. Has he or she been to the clinic with you?	
9. What might make it difficult to come to this clinic for your appointments?	
10. How will you remember to come for your clinic appointments?	
11. How will you remember to take your medicines the right way, at the same time, every day?	
12. Are you taking any medicines — other than the ones prescribed to you by the doctor or nurse (including traditional or herbal medicines)?	
13. Where will you store your medicines?	
14. What will you do if you are about to run out of your medicine(s)? What about if you are going to be away from home, such as when you are at school??	
15. What will you do if you miss a dose of your medicine?	
16. What questions do you have about the plan for your care or your medicines?	
17. Do you feel ready to start taking these medications?	

**Client requires more counselling and support in these areas (LIST):**

**Signature of person completing assessment:** \_\_\_\_\_ **Date:** \_\_\_\_\_

*Adapted from: ICAP. 2010. *Improving Retention, Adherence, and Psychosocial Support within PMTCT Services: A Toolkit for health workers.**

## Adherence Preparation/Support Guide for Assessing Caregivers' Readiness for ART

**Client's Name:** \_\_\_\_\_ **Client's Age:** \_\_\_\_\_ **Client's File#:** \_\_\_\_\_  
**Caregiver and/or Treatment Buddy's Name:** \_\_\_\_\_

Questions to ask the caregiver:	Notes
1. Can you tell me what support group or group education sessions you and your child have attended here at the clinic?	
2. Can you explain why your child needs to take ARVs?	
3. Who knows about your child's HIV status?	
4. What do you expect from your child taking ARVs?	
5. How do you feel about your child taking medicines every day for his or her lifetime?	
6. Can you tell me the names of the ARVs your child will be taking and when he or she will take them (how many pills, what times of day)?	
7. Can you tell me some possible side effects of your child's ARVs? What will you do if your child has side effects?	
8. Can you explain what happens if your child does not take all of his or her ARVs every day, at the same time?	
9. Who will help your child come to the clinic for appointments and help him or her take his or her medicines every day? What is your contact information/other supporters' contact information?	
9a. If someone other than the caregiver, has he or she been to the clinic with your child?	
9. What might make it difficult for your child to come to this clinic for his or her appointments?	
10. How will your child remember to come for his or her clinic appointments?	
11. How will your child remember to take his or her medicines the right way, at the same time, every day?	
12. Is your child taking any medicines — other than the ones prescribed to him or her by the doctor or nurse (including traditional or herbal medicines)?	
13. Where will you store the medicines?	
14. What will you do if you are about to run out of medicine(s)? What about if you or your child will be away from each other, or away from home, such as when he or she is at school?	
15. What will you do if the child misses a dose of the medicine?	

16. What questions do you have about the plan for your child's care or medicines?	
17. Do you feel that you and your child are ready to start taking these medicines?	

**Caregiver requires more counselling and support in these areas (LIST):**

**Signature of person completing assessment:** \_\_\_\_\_ **Date:** \_\_\_\_\_

Adapted from: ICAP. 2010. *Improving Retention, Adherence, and Psychosocial Support within PMTCT Services: A Toolkit for health workers.*

## **Appendix 8E: Adherence Assessment Guides**

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### **How to use these guides:**

These adherence assessment guides were developed to support a range of providers (trained counsellors, lay counsellors, Peer Educators, doctors, nurses, pharmacists, community healthcare workers, and others) who work with ALHIV and their caregivers. Routine adherence assessments help identify and solve specific adherence challenges in a timely manner. The adherence assessment guides should be adapted to reflect national HIV care and treatment guidelines, as well as the specific clinic, community, and cultural contexts in which they are used and for different ages of adolescent clients. It may be helpful to translate the guides into the local language.

**Included is one adherence assessment guide for adolescents enrolled in HIV care and treatment and one to be used with caregivers.** The guides should be used at every follow-up and refill visit to ensure that the adolescent client and caregiver understand the care and medication plan and that the client is taking his or her medicines the correct way, every day and/or that the caregiver is giving the client his or her medicines the correct way, every day. Completed adherence assessment forms should be kept in the client's file and referred to at follow-up visits.

### **Basic information:**

Write the client's name, age, and file number, as well as the caregiver or treatment buddy's name, at the top of the form. Then, tick the box corresponding to the type of visit. Be sure to sign and date the form at the end of each session, and keep in the client's clinic file.

### **Questions to ask the client/caregiver:**

The questions in this section allow the healthcare worker to discuss and assess adherence. It is important to allow time for the client/caregiver to respond to each question. Adolescent clients and caregivers should always be made to feel comfortable expressing adherence challenges and should never be judged or punished. Remember to write down any important information from their responses, as this will help decide on next steps, know important areas for follow up, and support the clients' adherence over the long term. If possible, the healthcare worker should meet with the client and caregiver separately to identify and address and discrepant responses. Meeting separately is especially important as young clients age into middle and late adolescence.

### **Other assessment measures and next steps:**

This is the section where healthcare workers will plan with the adolescent client/caregiver to ensure that the client keeps up good adherence or develops strategies to improve adherence.

- **Other adherence assessment measures:** Depending on standard procedures at the clinic, the healthcare worker may do a pill count and/or review the client's medicine diary or calendar. Record the results in the space provided.
- **Specific adherence challenges identified by the adolescent client, caregiver, and healthcare worker:** Based on the answers to the questions asked in the first section of this form, discuss the specific challenges to adherence that the client is having. Together, discuss possible solutions to each challenge.
- **Referrals made:** If there is an outside organisation, such as a youth support group or a home-based care programme, that could help support the client (and the caregiver and family) to overcome his or her challenges to adherence, refer the adolescent client (and/or caregiver) to that organisation or service and indicate the name and specific service in this part of the form. In some cases, the client (or caregiver) may need to be referred for other facility-based services, such as an appointment with a trained counsellor or a session with the pharmacist to explain dosing.
- **Next steps and follow-up plan:** Together with the adolescent client/caregiver identify which solutions and next steps he or she thinks are feasible and manageable. For each solution, list the necessary steps the client or healthcare worker will need to take and a time line for each. Also, make an appointment for a follow-up visit and record the date on the form. This section of the form can be used as a starting point for the adherence assessment during follow-up visits.

## Adherence Assessment for Adolescents Taking ART

**Client's Name:** \_\_\_\_\_ **Client's Age:** \_\_\_\_\_ **Client's File#:** \_\_\_\_\_

**Caregiver and/or Treatment Buddy's Name:** \_\_\_\_\_

**Tick one:**  2-week follow up    1-month follow up    monthly refill    3-month refill

Questions to ask the adolescent client:	Notes
1. Can you tell me more about how you took your medications this past month (or 2 weeks)? (Do you know the names of the medicines? How many pills do you take? At what time of day do you take them?)	
2. I would like you to think about the last 7 days. How many pills did you take late in the last 7 days?  What were the main reasons you took them late?	
3. How many pills did you miss in the last 7 days?  What were the main reasons you missed them?	
4. If we put all the pills you had to take in the last 2 weeks into one cup, this is what you would see. If you took all of them the cup would be empty. If you forgot to take all of them the cup would be full. Which of these pictures best shows how many of your doses you took in the last month (or 2 weeks)? (circle one)	
5. How did the medicines make you feel?	
6. Can you tell me about any changes you noticed (such as in your health) or challenges you had with your medicines?	
7. What support or reminders do you have to help you take your medicines at the same time, every day?	
8. What questions do you have about your care or your medicines?	

Other assessment measures and next steps:	Notes
Results of pill count, if applicable:	
Review of medicine diary or calendar, if applicable:	
Specific adherence challenges identified by the adolescent client, caregiver, and healthcare worker: (discuss possible solutions to each)	

Referrals made:	
Next steps and follow-up plan:	Next appointment date: _____

**Notes:**

**Signature of person completing assessment:** \_\_\_\_\_ **Date:** \_\_\_\_\_

*Adapted from: ICAP. 2010. Improving Retention, Adherence, and Psychosocial Support within PMTCT Services: A Toolkit for health workers.*

## Adherence Assessment for Caregivers of Adolescents Taking ART

Client's Name: \_\_\_\_\_ Client's Age: \_\_\_\_\_ Client's File#: \_\_\_\_\_

Caregivers Name: \_\_\_\_\_

Tick one:  2-week follow up  1-month follow up  monthly refill  3-month refill

Questions to ask the caregiver:	Notes
1. Can you tell me more about how your child took his or her medications this past month (or 2 weeks)? (Do you know the names of the medicines? How many pills does he or she take? At what time of day does he or she take them?)	
2. I would like you to think about the last 7 days. How many pills did your child take late in the last 7 days? What were the main reasons he or she took them late?	
3. How many pills did your child miss in the last 7 days? What were the main reasons he or she missed them?	
4. If we put all the pills your child had to take in the last 2 weeks into one cup this is what you would see. If he or she took all of them the cup would be empty. If he or she forgot to take all of them the cup would be full. Which of these pictures best shows how many of your child's doses he or she took in the last month (or 2 weeks)? (circle one)	
5. How did the medicines make your child feel?	
6. Can you tell me about any changes you or your child noticed (such as in your child's health) or challenges your child had with his or her medicines?	
7. What support or reminders does your child have to help him or her take his or her medicines at the same time, every day?	
8. What questions do you have about your child's care or your medicines?	

Other assessment measures and next steps:	Notes
Referrals made:	
Next steps and follow-up plan:	Next appointment date: _____

Notes:

Signature of person completing assessment: \_\_\_\_\_ Date: \_\_\_\_\_

Adapted from: ICAP. 2010. *Improving Retention, Adherence, and Psychosocial Support within PMTCT Services: A Toolkit for health workers.*



# Module 9 Positive Living for Adolescents



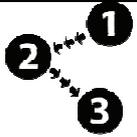
**Total Module Time:** 195 minutes (3 hours, 15 minutes)

## Learning Objectives

**After completing this module, participants will be able to:**

- Define positive living and describe the key components of positive living for adolescent clients.
- Describe the role of the healthcare worker in supporting ALHIV to achieve and maintain a healthy mind.
- Provide ongoing support and counselling to adolescent clients on maintaining a healthy body.
- Recognise signs of alcohol and drug use and abuse in adolescent clients and provide counselling and referrals.

## Methodologies



- Interactive trainer presentation
- Large group discussion
- Small group work
- Case studies
- Role play

## Materials Needed



- Slide set for Module 9
- Flip chart and markers
- Tape or Bostik
- Participants should have their Participant Manuals. The Participant Manual contains background technical content and information for the exercises.

## References and Resources



- Republic of Zambia, Ministry of Health, National Food and Nutrition Commission. 2004. *Nutrition Guidelines for Care and Support of People Living with HIV/AIDS*. Available at: [http://www.fantaproject.org/publications/zambia\\_guide2005.shtml](http://www.fantaproject.org/publications/zambia_guide2005.shtml)
- World Health Organization. *Integrated Management of Adolescent and Adult Illness and Integrated Management of Childhood Illness. 2007. Chronic HIV Care with ARV Therapy and Prevention: Interim Guidelines for Health Workers at*



	<p><i>Health Centre or District Hospital Outpatient Clinic. Geneva, Switzerland: WHO. Available at:</i> <a href="http://www.who.int/hiv/pub/imai/Chronic_HIV_Care7.05.07.pdf">http://www.who.int/hiv/pub/imai/Chronic_HIV_Care7.05.07.pdf</a>.</p> <ul style="list-style-type: none"><li>• World Health Organization, HIV/AIDS Programme. 2008. <i>Essential Prevention and Care Interventions for Adults and Adolescents Living with HIV in Resource-Limited Settings.</i> Geneva, Switzerland: WHO. Available at: <a href="http://www.who.int/hiv/pub/prev_care/OMS_EPP_AFF_en.pdf">http://www.who.int/hiv/pub/prev_care/OMS_EPP_AFF_en.pdf</a>.</li></ul>
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**Advance Preparation**

	<ul style="list-style-type: none"><li>• Read through the entire module and ensure that all trainers are prepared and comfortable with the content and methodologies.</li><li>• Review the appendices so that you can refer to them and integrate them into your presentation.</li></ul>
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### **Session 9.1: Supporting ALHIV to Live Positively and Maintain a Healthy Mind**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation and large group discussion	25 minutes
Questions and answers	5 minutes
Total Session Time	30 minutes

### **Session 9.2: Supporting ALHIV to Live Positively and Maintain a Healthy Body**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation and large group discussion	60 minutes
Exercise 1: Supporting ALHIV to Live Positively: Case studies and large group discussion	30 minutes
Exercise 2: Planning a Presentation on Living Positively: Small group work and large group discussion	60 minutes
Questions and answers	5 minutes
Review of key points	10 minutes
Total Session Time	165 minutes

## Session 9.1

# Supporting ALHIV to Live Positively and Maintain a Healthy Mind



**Total Session Time:** 30 minutes



### Trainer Instructions

Slides 1-4

- Step 1:** Begin by reviewing the Module 9 learning objectives and the session objectives, listed below.
- Step 2:** Ask participants if there are any questions before moving on.

### Session Objectives

**After completing this session, participants will be able to:**

- Define positive living and describe the key components of positive living for adolescent clients.
- Describe the role of the healthcare worker in supporting ALHIV to achieve and maintain a healthy mind.



### Trainer Instructions

Slides 5-8

- Step 3:** Start by asking participants to brainstorm what is meant by the phrase “positive living.” Record answers on flip chart and present the definition and formula for positive living.
- Ask participants about some of the ways they can share positive living information with adolescent clients. Remind participants that adolescents learn best from their peers and when information is presented through multiple modalities.
- Step 4:** Tell participants that this session reviews all of the ways that healthcare workers can support adolescents to have and maintain a healthy mind. The next session will focus on supporting adolescents to have and maintain a healthy body.



### Make These Points

- The concept “positive living” encompasses not only physical health but also taking care of the mind and soul.
- Healthcare workers should routinely address positive living with their adolescent clients. As ALHIV develop and age, so does their need for information about keeping healthy.

## What is Positive Living?

- Positive living includes:
  - Keeping the mind healthy (having a positive outlook toward living and life),
  - Keeping the body healthy,
  - Keeping the soul and spirit healthy (for example, the things we do to feel good on the “inside” and feel a sense of peace and contentment), and
  - Living responsibly with HIV and preventing new HIV infections.
- ALHIV can live full and healthy lives if they take care of themselves, access care and treatment, and feel supported to make healthy choices. This includes feeling supported by healthcare workers at the clinic.
- Caregivers and family members also play an important role in supporting ALHIV to live positively with HIV and prevent new HIV infections.
- Healthcare workers play a key role in helping ALHIV live positively and follow the “**recipe for positive living**” (see box below).

### **Recipe for positive living**

**KNOWLEDGE + DETERMINATION TO LIVE**

**with actions for a**

**HEALTHY MIND + HEALTHY BODY + HEALTHY SOUL**

**= A LONG, HEALTHY LIFE**

Source: Orr, N.M. 2004. *Positive health*. Cape Town: Double Storey Books.

Healthcare workers play an important role in helping adolescent clients learn about positive living. Because their questions and understanding of living with HIV changes over time, it is helpful to talk to adolescents on an ongoing basis about this topic. Information on positive living should be communicated repeatedly and through multiple channels, such as:

- Individual counselling sessions
- Individual health education sessions

- Group health education sessions (with adolescents alone, caregivers alone, or mixed groups)
- Support group meetings
- Youth-friendly written materials (such as flyers, brochures, books)
- TV shows or films about living positively
- Internet

A list of information web-based resources on positive living, geared towards young people, can be found in “Appendix 9A: Web Resources for ALHIV”.



### **Trainer Instructions**

Slides 9-19

#### **Step 5:**

Ask participants to think about earlier modules taught on this course. Ask:

- *What are some of the ways healthcare workers can support adolescents to have and maintain a healthy mind? (If needed, provide hints to encourage them to think about topics covered in previous modules, for example, peer support, psychosocial support, mental health support, and adherence and disclosure support).*

Introduce other ideas as well, including encouraging adolescents to stay in school and to participate in any spiritual or religious activities and rituals that comfort them.

#### **Step 6:**

Discuss life skills. Start the discussion by asking:

- *What do you think we mean by the term “life skills”?*
- *What are some of the most important life skills for ALHIV?*

Present the information on life skills and encourage discussion of ways in which healthcare workers can support adolescents to develop these skills.

#### **Step 7:**

(optional) Ask the adolescent co-trainer to share some of his or her ideas on how healthcare workers can support adolescent clients to have and maintain a healthy mind as part of positive living.



### **Make These Points**

- Although adolescents have to ultimately reach within themselves to ensure their minds are healthy, healthcare workers can do much to

assist adolescents to find emotional and psychosocial health.

- Healthcare workers can recommend and connect ALHIV to peers and peer support groups. They can also provide psychosocial and mental health screening and support. The multidisciplinary team has a key role in supporting disclosure and providing adherence support. Healthcare workers can also encourage adolescents to stay in school and/or pursue a career and to maintain their spiritual practices.
- Life skills education can help adolescents develop into stronger, more aware, and more caring human beings equipped to cope with the demands and pressures of everyday life and living with HIV. Life skills can also help adolescents assess risks and make decisions that will lead to positive outcomes and a better, healthier life. In their work with adolescents, healthcare workers can promote the development of these life skills.

## **Supporting Adolescents to have Healthy Minds**

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### **Ensure that adolescent clients have access to adolescent-specific support groups and peer support (see Module 5)**

- Healthcare workers should take part in creating and facilitating peer support groups in the clinic and should also link ALHIV with any existing support groups.
- Peer support can engage and help support the psychosocial needs of ALHIV, and can help them improve access and adherence to HIV prevention, care, and treatment services.

### **Ensure that psychosocial support and mental health services are part of comprehensive HIV care and treatment (see Modules 5 and 6)**

- ALHIV face additional challenges and stressors as a result of living with a chronic, highly stigmatised disease. They are also more susceptible to many mental health challenges, which often emerge in late childhood and early adolescence. Adolescents need support not only with mental health issues but also with everyday issues such as the desire to be normal to accept HIV-related care.
- It is important to provide ALHIV with routine psychosocial and mental health assessments and support as an integral part of their care. They will likely need extra support during challenging times, such as when they are preparing to disclose their status, when they lose a loved one, when they face discrimination, etc.

### **Ensure that adequate attention is paid to ongoing disclosure support for caregivers and for adolescent clients (see Module 7)**

- Disclosure is a process, and not a one-time event. Both ALHIV and caregivers need ongoing support on issues related to disclosure.
- Healthcare workers can help adolescents overcome their fear of disclosure to others by helping them see the advantages to having trusted people know their status. They can also help them decide whom

to disclose to, when and where, to weigh the advantages and disadvantages, and to help them anticipate likely responses.

**Ensure that adolescent clients (and caregivers) receive ongoing adherence support (see Module 8)**

- There are many barriers and challenges to retaining adolescents in care and to supporting adolescents to adhere to their ART regimen. Although healthcare workers may not be able to address all of the client's barriers to adherence, there are many factors that can be addressed, such as minimising health service barriers by improving the quality of counselling and ensuring access to youth-friendly services.
- There is no one specific way to monitor adherence. The best way is to use many different methods, such as routine adherence assessment, ongoing adherence counselling, review of clinical and laboratory records, pill count, etc. When helping clients and caregivers prepare for ART, always address the WHO, WHAT, WHEN, WHERE, and HOW of the medications.

**Encourage adolescents to go to and stay in school**

- Adolescents who stay in school will have more opportunities in the future.
- In addition to building academic skills, school also provides a chance for adolescents to make friends and to develop life skills.

**Talk with adolescents about their spiritual and/or religious beliefs and practices**

- Healthcare workers should encourage both ALHIV and their families to continue their regular religious or spiritual practices.
- For those who have grown up with a spiritual and/or religious element in their family or community, this can be a further source of support and counselling to help them face issues related to mental health, disclosure, and positive living.

**Encourage adolescent clients to develop life skills and to help them live positively with HIV (see below).**

**Supporting Adolescents to Develop Life Skills<sup>1</sup>**

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Having life skills helps adolescents to be confident, knowledgeable, and able to take responsibility for their own lives. Life skills education can help adolescents develop into stronger, more aware, and more caring human beings equipped to cope with the demands and pressures of everyday life and living with HIV. Life skills can also help adolescents assess risks and make decisions that will lead to positive outcomes and a better, healthier life.

There is no definitive list of life skills, but a sample list is included in Table 9.1, below. This list encompasses psychosocial and interpersonal skills that

are generally considered important for adolescents as they grow, develop, and manage their chronic illness.

Healthcare workers are not responsible for teaching adolescent clients all of these life skills, but should keep them in mind when working with adolescents and providing psychosocial support. They should also encourage life skills trainings and discussions as part of peer activities and support groups. When possible, healthcare workers can link their adolescent clients with formal or informal life skills trainings, for example, trainings offered by youth groups, schools, or community organisations.

**Table 9.1: Examples of adolescent life skills**

<b>Communication and Interpersonal Skills</b>	<b>Decision-making and Critical Thinking Skills</b>	<b>Coping and Self-Management Skills</b>
<p><b>Interpersonal communication skills:</b></p> <ul style="list-style-type: none"> <li>• Verbal communication</li> <li>• Non-verbal communication</li> <li>• Expressing feelings</li> <li>• Giving and receiving feedback</li> </ul> <p><b>Negotiation/refusal skills:</b></p> <ul style="list-style-type: none"> <li>• Negotiation and conflict management</li> <li>• Assertiveness skills</li> <li>• Refusal skills</li> </ul> <p><b>Empathy:</b></p> <ul style="list-style-type: none"> <li>• Ability to listen and understand another’s needs and circumstances and express that understanding</li> </ul> <p><b>Cooperation and Teamwork:</b></p> <ul style="list-style-type: none"> <li>• Expressing respect for others’ contributions and styles</li> <li>• Assessing one’s own abilities and contributing to the group</li> </ul> <p><b>Advocacy skills:</b></p> <ul style="list-style-type: none"> <li>• Influencing skills and persuasion</li> <li>• Networking and motivation skills</li> </ul>	<p><b>Decision-making and problem solving skills:</b></p> <ul style="list-style-type: none"> <li>• Information gathering skills</li> <li>• Evaluating future consequences of present actions for self and others</li> <li>• Determining alternative solutions to problems</li> <li>• Analysis skills related to the influence of values and attitudes on motivation (of self and others)</li> </ul> <p><b>Critical thinking skills:</b></p> <ul style="list-style-type: none"> <li>• Analysing peer and media influences</li> <li>• Analysing attitudes, values, social norms, and beliefs and factors affecting these</li> <li>• Identifying relevant information and sources of information</li> </ul>	<p><b>Skills for increasing internal locus of control:</b></p> <ul style="list-style-type: none"> <li>• Self-esteem/confidence building skills</li> <li>• Self awareness skills, including awareness of rights, influences, values, attitudes, strengths, and weaknesses</li> <li>• Goal setting skills</li> <li>• Self-evaluation, self-assessment, and self-monitoring skills</li> </ul> <p><b>Skills for managing feelings:</b></p> <ul style="list-style-type: none"> <li>• Anger management</li> <li>• Dealing with sadness, grief, and anxiety</li> <li>• Coping skills to deal with loss, abuse, illness, and trauma</li> </ul> <p><b>Skills for managing stress:</b></p> <ul style="list-style-type: none"> <li>• Time management</li> <li>• Positive thinking</li> <li>• Relaxation techniques</li> </ul>

Source: UNICEF. 2004. “Which skills are life skills?” Available at: [http://www.unicef.org/lifeskills/index\\_whichskills.html](http://www.unicef.org/lifeskills/index_whichskills.html)



### **Trainer Instructions**

**Step 8:** Allow 5 minutes for questions and answers on this session.

## Session 9.2

# Supporting ALHIV to Live Positively and Maintain a Healthy Body



**Total Session Time:** 165 minutes (2 hours, 45 minutes)



### Trainer Instructions

Slides 20-21

- Step 1:** Begin by reviewing the session objectives listed below.
- Step 2:** Ask participants if there are any questions before moving on.

### Session Objectives

**After completing this session, participants will be able to:**

- Provide ongoing support and counselling to adolescent clients on maintaining a healthy body.
- Recognise signs of alcohol and drug use and abuse in adolescent clients and provide counselling and referrals.

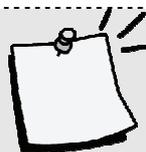


### Trainer Instructions

Slides 22-29

- Step 3:** Ask participants:
- *What are some of the ways that healthcare workers can support adolescents to have and maintain a healthy body?*
- Give them about 10 minutes to come up with as many of the components of “positive living” as possible. Record answers on flip chart fill in using Table 9.2.
- Explain that some of these topics will be explored further during this session and in the next module.
- Step 4:** Ask participants:
- *What do you think we mean by “positive prevention”?*
  - *What are some examples of “positive prevention”?*
- Write responses on flip chart and fill in using the content below. Remind participants that many of these topics will be included in Module 10: Sexual and Reproductive Health.

**Step 5:** (optional) Encourage the adolescent co-trainer to give specific inputs on the challenges ALHIV face with positive living and positive prevention, and the things healthcare workers can do to be supportive.



### Make These Points

- Healthcare workers should actively encourage ALHIV to live healthy. Examples of healthy living include using condoms in combination with an additional family planning method, attending routine healthcare, taking prescribed medicines exactly as recommended, staying active, making friends, getting rest, eating healthy, and exercising regularly.
- Habits to avoid include drinking alcohol, taking drugs, smoking, and eating poorly.
- “Positive prevention” refers to the prevention of the further transmission of HIV. Positive prevention includes disclosure to sexual partners, safer sex, and PMTCT interventions.

## Key Points for Positive Living

### Healthy behaviours

Healthcare workers should actively encourage ALHIV to live healthy. Some of the activities that constitute “living healthy” or “living positively” are summarised in Table 9.2.

**Table 9.2: Positive living**

<b>“Living positively” with HIV includes...</b>
<b>Healthcare</b>
<ul style="list-style-type: none"> <li>• Going to the hospital or clinic for checkups, lab tests, and to pick up medicines. Never miss an appointment.</li> <li>• Taking medicines the right way (at the right time, the right number, etc.).</li> <li>• Informing healthcare workers if taking any traditional remedies or supplements.</li> <li>• Telling a nurse or doctor if there are any health-related changes, even small ones.</li> </ul>
<b>Sexual health</b>
<ul style="list-style-type: none"> <li>• If sexually active, using condoms and practising safer sex every time; using a family planning method in addition to condoms (dual protection).</li> <li>• Getting screened for STIs and, if infected, getting treatment immediately and referring partners for treatment.</li> </ul>
<b>Staying active and socially engaged</b>
<ul style="list-style-type: none"> <li>• Taking physical exercise (walking, jogging, and light household</li> </ul>

chores) to build muscles, reduce stress, and improve appetite.
<ul style="list-style-type: none"> <li>• Staying socially engaged: making new friends and accessing peer support through youth clubs, sports teams, and/or after-school clubs; joining an ALHIV association; talking about things openly.</li> <li>• Staying in school/at work and prioritising education/career.</li> </ul>
<b>Rest</b>
<ul style="list-style-type: none"> <li>• Getting enough rest.</li> <li>• Sleeping and resting under an insecticide-treated mosquito net if in a malarial area.</li> </ul>
<b>Personal hygiene</b>
<ul style="list-style-type: none"> <li>• Washing hands with soap often, especially: <ul style="list-style-type: none"> <li>• After using the toilet, touching the genitals, or touching any body fluid.</li> <li>• Before preparing food or eating.</li> <li>• After sneezing or coughing.</li> <li>• After handling garbage.</li> <li>• After touching animals.</li> </ul> </li> <li>• Bathing regularly.</li> <li>• Practising good hygiene during the menstrual period: <ul style="list-style-type: none"> <li>• Changing sanitary pads or cloths regularly.</li> <li>• Washing hands before and after changing sanitary products.</li> <li>• Bathing daily during the monthly period (note: there is never a need to clean inside the vagina, not even during the monthly period).</li> <li>• Safely disposing (by putting into a pit latrine or burning) or washing used sanitary pads/clothes.</li> </ul> </li> </ul>
<b>Oral health</b>
<ul style="list-style-type: none"> <li>• Keeping your mouth clean by brushing teeth, mouth, and tongue at least twice a day.</li> <li>• Treating severe oral lesions with gauze soaked in salt water to clean the mouth.</li> </ul>
<b>Nutrition</b>
<ul style="list-style-type: none"> <li>• Eating enough healthy food and taking multivitamins.</li> <li>• Drinking at least 8 glasses (250 mls/glass) of clean water each day. People with HIV should always drink water that has been boiled or treated with chlorine liquid or tables (for example, “WaterGuard”).</li> </ul>
<b>Food hygiene</b>
<ul style="list-style-type: none"> <li>• Washing food preparation, cooking, eating, and storage utensils with soap and hot water.</li> <li>• Washing raw fruits and vegetables well with clean water.</li> <li>• Covering food to prevent both flies and dust from contaminating it; not storing raw and cooked foods together.</li> <li>• Eating food as soon as it is cooked. Not storing leftovers unless they can be kept in a refrigerator or a cool place.</li> <li>• Cooking food thoroughly, particularly meat, poultry, and fish. Meat should have no red juices; however, remember that overcooking vegetables causes them to lose nutritional value.</li> <li>• Keeping the house and compound clean — getting rid of any still water,</li> </ul>

keeping garbage covered, and disposing it at least daily.

- Keeping all food preparation surfaces clean. Use a germ-killing bleach solution (like Jik, or Gention Violet) diluted with water to keep household surfaces clean. If using Jik for home disinfecting, mix one part Jik to 10 parts water. When using Jik in healthcare settings (for example, disinfecting instruments such as blades and needles), use one part Jik to six parts of water and soak at least 10 minutes.

## Unhealthy behaviours

Healthcare workers should talk with ALHIV about avoiding practices or behaviours that are not healthy. These include:

- Drinking alcohol
- Using drugs
- Smoking cigarettes
- Having unsafe sex
- Avoiding social contact and staying alone too much
- Sharing medicines, stopping medicines without talking to the doctor, or missing medication doses
- Missing appointments at the clinic
- Taking traditional medicines that have not been discussed with the doctor or nurse
- Not eating enough healthy foods or eating too many sugary or fatty foods

## Helping Clients Practise Positive Prevention

Positive prevention is a key component of positive living. Healthcare workers are responsible for discussing with ALHIV ways to prevent the further spread of HIV to sexual partners and children. Positive prevention includes:

- Partner disclosure and testing,
- Sexual risk reduction and sexual health (see Module 10),
- Prevention and treatment of STIs (see Module 10),
- PMTCT (see Module 10), and
- Prevention of blood-borne HIV transmission, including transmission through injecting drug use, sharing sharp instruments to cut or pierce the skin.



### Trainer Instructions

Slides 30-33

#### Step 6:

Ask participants to comment on the nutritional challenges they see in adolescent clients. Use these questions to guide the discussion:

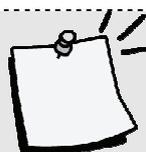
- *What are the common nutritional challenges you see in adolescent clients (and their families)?*
- *Other than lack of food/money to buy food, what are some of*

*the common challenges adolescents have with good nutrition (for example, eating a lot of “junk” food)?*

- *What does it mean to eat a “balanced” diet?*

Discuss the importance of eating a balanced diet, referring participants to “Appendix 9B: Basic Food Groups”.

**Step 7:** (optional) Ask the adolescent co-trainer to comment on the challenges ALHIV face in eating well and what he or she thinks healthcare workers can do to support good nutrition among their adolescent clients.



### **Make These Points**

- In addition to the challenges their families face in eating healthy, ALHIV typically face additional barriers to good nutrition, including erratic eating patterns and loss of appetite.
- Encourage ALHIV to avoid eating “junk foods” — they cost a lot of money and have little nutritional value.
- It is particularly important for ALHIV to eat a “balanced diet”, that is, eating a variety of foods from each of the 3 food groups.

## **Review of General Nutrition Information<sup>2</sup>**

### **Common nutritional issues for adolescents:**

- Many adolescents — especially the most vulnerable adolescents, such as orphans, street youth, and others — face food insecurity.
- Many adolescents develop bad eating habits — such as eating a lot of “junk food” (see box, below), skipping meals, and having erratic eating patterns given their busy lifestyles.
- Some ARVs may cause adolescents to lose their appetite and some may cause weight changes, such as lipodystrophy.

### **Junk food**

Sometimes when adolescents are very busy or do not have time to prepare food, they (and their families) eat pre-prepared foods and “junk foods”. Healthcare workers should help clients understand why they should avoid “junk foods” like soft drinks, sweets, and potato chips/crisps — they cost a lot of money and have little nutritional value. Fresh, natural foods are always the best and are usually cheaper than packaged and pre-prepared foods.

**It is critically important to provide regular weight and nutrition monitoring as part of routine care for ALHIV.**

### **Eating a “balanced diet”**

Eating a “balanced diet” means eating a variety of foods from each of the 3 food groups (see “Appendix 9B: Basic Food Groups”) and eating enough food every day. It is always best to eat foods that are grown at home or produced locally instead of imported or processed foods, which do not have as many nutrients.

For additional information on healthy eating for people living with HIV, see the Zambia Ministry of Health’s *Nutrition Guidelines for Care and Support of People Living with HIV/AIDS*.



#### **Trainer Instructions**

Slides 34-43

**Step 8:** Ask participants to discuss the relationship between nutrition and HIV, why good nutrition is so important for the health and development of ALHIV, and the goals of nutritional support. Start by asking:

- *What is the relationship between nutrition and HIV? Hint: the cycle starts because HIV increases nutrient requirements.*
- *What do you think healthcare workers can do to help ALHIV and their caregivers/families eat well?*
- *What nutrition-related recommendations do you give ALHIV and their caregivers?*

Fill in using the content below.

**Step 9:** Provide an overview to the nutrition assessment, referring participants to “Appendix 9C: Key Components of a Nutritional Assessment”.

Then provide an overview of common nutritional and eating problems. Take about 5–7 minutes to ask participants the following questions to encourage discussion on food-related remedies to common HIV-related problems. Feel free to skip some of these questions to save time, what is important for now is to familiarise participants with “Appendix 9C: Key Components of a Nutritional Assessment” so they know where to go to after the training.

- *When a client is losing weight, what food-based remedies would you recommend?*
- *What food or nutrition-based interventions do you recommend for anaemia?*
- *How about diarrhoea? Nausea and vomiting? Mouth and throat sores? Loss of appetite? Taste changes?*

Answers to these questions can be found in “Appendix 9D: Nutritional Management of Common Symptoms Related to Advanced HIV Infection”.

**Step 10:** Finally, discuss how you can advise a client who lacks access to food. Ask:

- *What do you do if adolescents and their families do not have enough food to eat? What are some strategies that could work in your setting?*

**Step 11:** Fill in anything that participants left out during the previous discussion to make sure that all the aspects of ongoing nutritional assessments and provision of nutritional counselling have been covered. Remind participants that they should refer to the national nutrition guidelines for the care and support of PLHIV for more information.



### **Make These Points**

- The relationship between nutrition and HIV is cyclical. It starts with HIV increasing nutrient requirements and reducing nutrient intake and absorption. This, in turn increases the risk of malnutrition. Then malnutrition increases the risk of opportunistic infections and speeds the progression of HIV to AIDS.
- Conversely, good nutrition can strengthen the immune system, delay or prevent OIs, and increase quality and length of life.
- ALHIV should eat a well-balanced diet that includes a variety of fresh foods from all three of the food groups. ALHIV will notice that they will need to eat more (perhaps an additional snack or additional meal every day) just to keep from losing weight.
- Healthcare workers need to monitor nutritional and health status by weighing their adolescent clients at each visit, recording their weight in the patient chart, and looking for and asking about changes.
- Many HIV-related signs and symptoms — such as anaemia, diarrhoea, nausea, vomiting, mouth and throat sores and loss of appetite — can be prevented or even treated through food-based interventions.
- Many clients do not take enough to eat because of a lack of food or insufficient funds to purchase enough foods. Healthcare workers will need to be prepared to provide advice and referrals to these clients.

## Helping ALHIV to Eat Well

### The relationship between nutrition and HIV

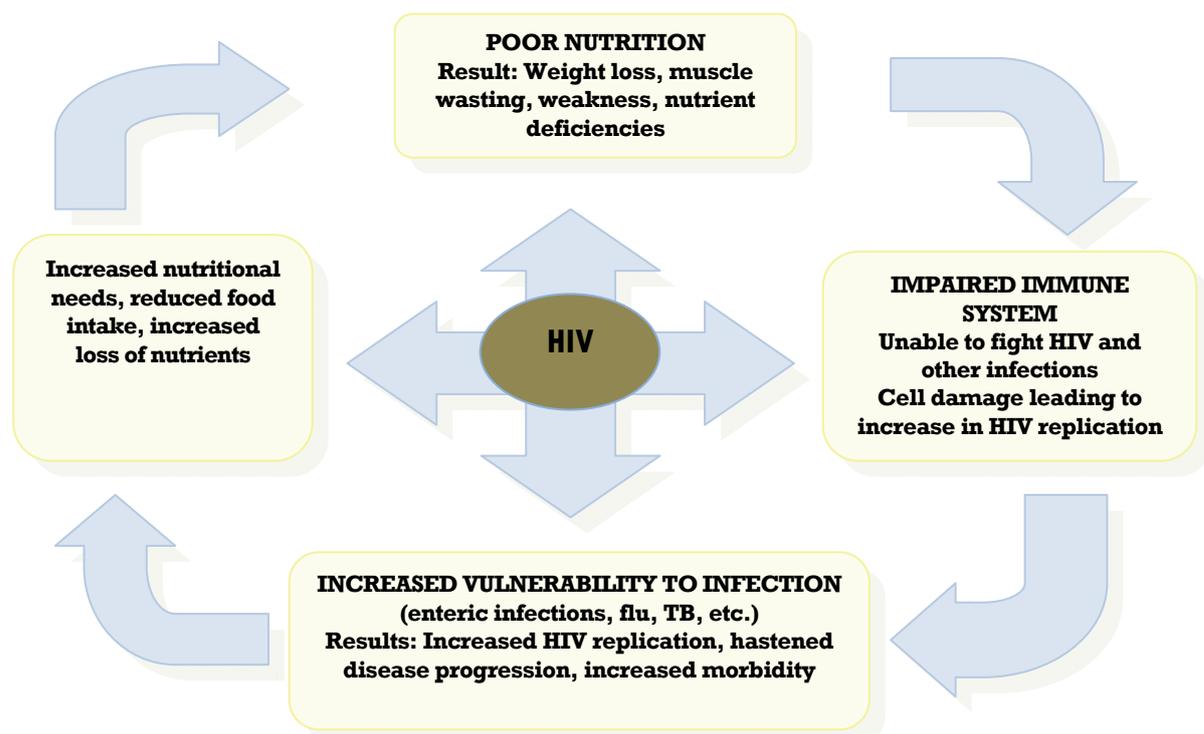
Good nutrition can play an important role in the care and management of HIV. The effect of HIV on the body's nutritional status begins early in the course of the infection, even before symptoms are seen. Conversely, good nutrition has the greatest impact at the early stages of HIV, strengthening the immune system to fight OIs and delaying disease progression.

The relationship between nutrition and HIV is cyclical:

- HIV infection increases nutrient requirements and reduces nutrient intake and absorption.
  - This increases the risk of malnutrition.
  - Malnutrition increases the risk of opportunistic infections and speeds the progression of HIV to AIDS.

Poor nutrition and HIV together create a vicious cycle that weakens the immune system, as illustrated in Figure 9.1 below.

**Figure 9.1: Cycle of malnutrition and infection in the context of HIV**



Source: Zambia Ministry of Health, National Food and Nutrition Commission. 2004. *Nutrition Guidelines for Care and Support of People Living with HIV/AIDS*. Available at: [http://www.fantaproject.org/publications/zambia\\_guide2005.shtml](http://www.fantaproject.org/publications/zambia_guide2005.shtml)

## **The goals of providing nutritional support to ALHIV**

The goals of nutrition support include:

- Preventing weight loss and maintaining optimal nutrition status.
- Restoring nutritional status for severely malnourished patients in order to optimise health.
- Supporting overweight patients to lose weight and reduce the associated health risks.

## **General nutrition recommendations for ALHIV:**

- Eat a well-balanced diet that includes a variety of fresh foods, based on what is locally available and affordable.
  - Make “energy giving foods” (starches) the biggest part of every meal.
  - Eat “body building foods” with every meal. Whenever possible, a meal should contain some meat, fish or other foods from animals as often as the client can afford them. Plant proteins (beans, peas, soya beans, peanuts, and other nuts), when properly combined, also provide good quality protein.
  - Eat fruits and vegetables every day.
  - Use fats and oils in moderation.
  - Avoid junk food and processed foods.
- Increase caloric intake, especially with “energy giving” and “body building” foods.
  - Asymptomatic ALHIV require between 10–15% more energy intake than people without HIV. They require an extra snack or additional small meal each day just to maintain their current weight.
  - Symptomatic ALHIV require between 20–30% more energy intake. This translates to another full meal each day or 2–3 additional snacks.
- Try to eat small meals frequently and have a regular meal schedule (remember, adolescents often have erratic eating patterns given their busy lives)
- Have their weight routinely monitored and recorded. If there are changes, or other indications of nutritional problems, the healthcare worker should conduct a nutritional assessment (see next section).
- Receive nutritional education and counselling (along with their caregivers) as a part of all HIV care appointments.
- Receive a daily multivitamin supplement as a routine part of care in order to prevent micronutrient deficiencies.

Many of the activities listed in “Table 9.2: Positive living” will enhance appetite (for example, taking exercise), aid digestion (for example, drinking plenty of water) and prevent food-related illness (for example, practising good food hygiene).

## Conducting a Nutritional Assessment

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Healthcare workers should follow national guidelines on nutrition assessment and be sure to:

### **Weight monitoring**

It is important to weigh **EVERY** client at **EVERY** visit. Their weights should be charted, or at least recorded in a table, for easy comparison with previous weights. **Even adolescents who have stopped growing and adults need to be weighed at every visit!**

- Weigh adolescent clients at each visit, record their weight in the patient chart, and look for and ask about changes.
- Conduct anthropometric, clinical, and dietary (and biochemical, where available) assessments regularly.

A summary of key anthropomorphic assessments and their interpretation is included as “Appendix 9C: Key Components of a Nutritional Assessment”.

The goal of nutritional assessment is to determine if nutritional problems exist and if so, the severity of nutritional problems and probable causes. Healthcare workers should consider the high incidence of food insecurity for families in Zambia, especially those affected by HIV. Every nutritional assessment should include a discussion of the ability of the client and his or her family to buy or grow enough healthy foods to eat. Nutritional counselling, education, and advice should always be adapted to the realities of clients’ situations.

## Common Nutritional and Eating Problems and Advice for Adolescent Clients and Caregivers

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Many health-related symptoms can be prevented or even treated through food-based interventions. Healthcare workers should try to support adolescent clients with nutritional problems and work with them and or their caregivers to address them with home-based nutrition interventions. Prompt treatment of symptoms can support clients to adhere to their care and treatment plan, including ART, which, in turn, can prevent or reduce many symptoms. See “Appendix 9D: Nutritional Management of Common Symptoms Related to Advanced HIV Infection” for more information.

## What to Do When Clients and Families Do Not Have Enough Food

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One of the most common challenges ALHIV and their families face is lack of food. Some ways healthcare workers can help ALHIV and their families get or grow enough good foods to eat include the following:

- Provide practical counselling and education on good nutrition, gardening, purchasing locally available foods, and how to store and prepare food.
- Make sure clients take multivitamins.
- Work with the rest of the multidisciplinary team to have formal linkages between the clinic and agricultural and food support organisations, including food distribution to clients at the health facility level.
- Link clients with agricultural support programmes in the community.
- Link clients with nutrition support programmes in the community.
- Link clients with animal husbandry, agricultural, and other income-generating activities in the community.



### **Trainer Instructions**

Slides 44-55

#### **Step 14:**

Ask participants to comment on the challenges they see in adolescent clients related to alcohol and drugs. To guide discussion ask:

- *What are some of the common challenges adolescents have related to alcohol and drug use?*
- *What are some causes and consequences of drug and alcohol use among adolescents?*
- *How do you recognise substance abuse? What are some signs/symptoms?*
- *What services related to alcohol and drug use do you currently provide to clients living with HIV?*

Review the screening and management tools in “Appendix 9E: Screening and Management of Alcohol Dependency” and “Appendix 9F: Screening and Management of Drug Abuse”. (You do not need to go through these appendices in detail, but participants need to know the tools are in this curriculum, so they can refer to them in future.)

Then ask

- *What do you think healthcare workers can do to help ALHIV avoid or recover from a problem with alcohol and drugs?*

#### **Step 15:**

(optional) Ask the adolescent co-trainer to comment on the challenges ALHIV face with drugs and alcohol and what he or she thinks healthcare workers can do to support adolescents to deal with issues related to alcohol and drugs.



### **Make These Points**

- Healthcare workers can help adolescents avoid substance use as well as help those clients using or abusing drugs and alcohol by providing counselling and support. This can include risk reduction counselling and referrals to more intensive treatment if needed and available.
- The consequences of substance abuse can include poor adherence to HIV care and treatment, risky sexual practices, and juvenile crime. Adolescent substance abuse is associated with problems in school as well as developmental problems and physical ailments.
- Healthcare workers should watch for signs of alcohol misuse and abuse in their clients and screen for abuse. Those who are identified as abusing substances need education, counselling and referrals.

## **Helping Clients Avoid Alcohol and Drugs<sup>3,4</sup>**

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### **Substance use versus abuse**

Not everyone who uses drugs becomes addicted, but substance use and abuse can cause problems for individuals whether they are addicted or not. There are different levels of substance use:

1. Social or recreational use
2. More frequent use
3. Physical dependence or addiction to the substance

Healthcare workers can help adolescents avoid substance use in the first place, and can also help those clients using or abusing drugs and alcohol by providing counselling and support, including risk reduction counselling, and referrals to more intensive treatment if needed and available.

### **Drugs and alcohol: A part of everyday life for many adolescents**

- Many adolescents face a lot of challenges and temptations when it comes to drugs and alcohol.
- People sometimes drink or use drugs to take away their worries. However, using drugs or drinking alcohol to cope with sadness or stress will only make a person feel physically and emotionally worse in the long term, even if it makes them feel better initially.
- When people take drugs or alcohol, they may become addicted, which means that their body starts to need the substance and that they feel unwell if they do not get it.
- People who are addicted to drugs and alcohol often do not eat well because they spend most of their money on drugs and alcohol rather than on food. Also, drugs and alcohol can affect your appetite.
- Helping adolescents learn about the risks of drugs, alcohol, and cigarettes before they start using them helps prevent addiction and harmful effects. This can be done through individual counselling and health education sessions and through group health education sessions with adolescents (and caregivers).
- Screening adolescent clients for alcohol and drug use, and providing counselling, referrals, and treatment for adolescents who abuse substances are key components of adolescent HIV care and treatment. They are also important aspects of supporting ALHIV to live positively.

### **Predictors of abuse**

Some predictors of drug and alcohol abuse include:

- **Family factors:** Adolescents who observe their parents or close family members using or abusing drugs or alcohol, are more likely to use or abuse substances themselves. Other family risk factors include parental absence, inconsistent discipline, lack of communication within the family, conflict between parents and adolescents, death of parents due to HIV, and family breakup. Drug use is most prevalent among ALHIV who do not have strong support systems.
- **Peer factors:** Spending time with peers who use drugs is perhaps the strongest predictor of adolescent substance use.
- **Mental health problems:** There is a strong link between mental health problems and substance abuse.
- **Response to stress:** Substance and drug use in adolescents may be the result of feeling out of control, a sense of meaninglessness, or a lack of direction in life. Adolescents may use drugs to feel better about life events, which they see as being out of their control.

### **Consequences of adolescent substance abuse**

Adolescents face unique risks associated with substance abuse and are at risk for a number of problems, including the following:

- **Poor adherence to HIV care and treatment:** Substance abuse has a significant negative impact on an individual's adherence to HIV care and medications.
- **School-related problems:** Adolescent substance abuse is associated with declining grades, absenteeism from school, and dropping out of school.
- **Risky sexual practices:** Adolescents who use drugs and alcohol are more likely than non-using adolescents to have sex, initiate sex at a younger age, and have multiple sex partners. As substance abuse reduces their ability to practise safer sex, they are at greater risk for unplanned pregnancies, passing HIV, and passing or acquiring other sexually transmitted infections.
- **Delinquent behaviour and juvenile crime:** Drug use can lead to selling drugs, stealing, and violent behaviour.
- **Developmental problems:** Exposing the brain to alcohol during adolescence may interrupt key processes of brain development, possibly leading to mild cognitive impairment.
- **Physical and mental consequences:** Substance abuse has negative effects on the user's mind and body. The effects can be short-term, such as memory loss or high blood pressure, or long-term, such as certain cancers (for example, upper digestive tract cancers from alcohol abuse, lung cancer from smoking), heart or respiratory failure, stomach ailments, central nervous system damage, and sexual impotence. Alcohol use also interacts with conditions such as depression and stress to contribute to suicide. Some studies have shown that drinking alcohol may accelerate their HIV disease progression, as both HIV and alcohol suppress the body's immune system.

### **Prevention of substance abuse**

Prevention strategies should be linked to the overall goal of prevention or less harm/safer use. Some substance abuse prevention education strategies healthcare workers may use include:

- Ensuring ALHIV have positive peer support networks and are linked to support groups.
- Counselling clients to increase their awareness of the consequences of alcohol and drug use.
- Counselling clients on risk reduction to enhance healthy lifestyle decision-making ability.
- Ensuring clients receive psychosocial support to help them develop a range of positive coping skills (see Module 5).
- Ensuring clients with mental health problems or disorders receive support and treatment (see Module 6).

### **Signs and Symptoms of Substance Abuse**

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Healthcare workers should be alert to changes in an adolescent's behaviour and appearance that may signal substance abuse. The following behaviour changes, when extreme or lasting for more than a few days, may

indicate alcohol- or drug-related problems and the need for further screening by a qualified counsellor, social worker, or mental health professional.

- Sudden changes in personality without another known cause
- Loss of interest in favourite hobbies, sports, or other activities
- Sudden decline in performance or attendance at school or work
- Changes in friends and reluctance to talk about new friends
- Deterioration of personal grooming habits and personal hygiene
- Difficulty paying attention or forgetfulness
- Sudden aggressive behaviour, anger, nervousness or giddiness
- Increased secretiveness, heightened sensitivity to being asked questions
- Sudden changes or unexplained problems with adherence to medications or missed appointments

### **Alcohol use and abuse**

Healthcare workers should watch for signs of alcohol misuse and abuse among their patients and provide education on risk reduction and referrals for counselling and treatment. Where available, clients may find support groups specifically for alcoholics (such as Alcoholics Anonymous) very helpful. When medically necessary, detoxification is offered at, for example, Chainama Hospital.

Screen for alcohol misuse upon initial intake and whenever suspected based on medical history, report from family/partner, behaviour in the clinic, or findings from any of the psychosocial assessments (for example, the Assessment of Well Being Screening Tool, in Table 6.1, Module 6; or the HEADSS Interview Questions in Appendix 3B, Module 3). “Appendix 9E: Screening and Management of Alcohol Dependency” provides guidance on screening for and managing alcohol dependency.

### **Use and abuse of other drugs**

Healthcare workers should watch for signs that adolescent clients are abusing other drugs. In addition to alcohol, marijuana, glue (sniffing), and methamphetamines are commonly used in Zambia. There is also increasing evidence that some ARVs are being abused; for instance, efavirenz is sometimes crushed and smoked.

Screen for drug use and abuse upon initial intake and whenever suspected based on the medical history, report from family/partner, behaviour in the clinic, or findings from any of the psychosocial assessments (for example, the Assessment of Well Being Screening Tool, in Table 6.1, Module 6; or the HEADSS Interview Questions in Appendix 3B, Module 3). “Appendix 9F: Screening and Management of Drug Abuse” provides guidance on screening for and managing drug abuse. If drug abuse is suspected,

provide supportive counselling and make referrals for ongoing counselling and detoxification.

## **Working with Clients who Show Signs of Substance Abuse**

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When working with clients who show signs of substance abuse, healthcare workers can:

- Be patient and accepting of the client's situation. Individuals with substance abuse problems can be very resistant to behaviour change, and recovery can be a gradual process.
- Provide ongoing support and follow up. At every visit, ask ALHIV in recovery about the date of last use of substances.
- Counsel the client about risks associated with use.
- Teach the client to identify and resist peer group and family pressure (for example, role play communication skills).
- Counsel the client on behaviour change, risk reduction, and safer sex practices.
- Emphasize values and attitudes that support non-use or safe use (i.e., risk reduction, for example, using clean needles) where possible.
  - Refer the client to group counselling or a peer support group, if available. Support groups are an effective treatment model because they offer opportunities for these clients to learn that their concerns are not unique.
  - Refer client to any psychiatric and/or community-based support services for life skills training and substance abuse treatment. Healthcare workers should maintain open lines of communication with the referral facility to monitor client's progress and treatment plan.

### **Support and treatment for ALHIV with substance abuse problems**

- Healthcare workers should ensure that HIV-infected adolescents are enrolled in HIV care regardless of whether or not they are actively using drugs.
- Many adolescents can benefit from ongoing counselling, including risk education and risk reduction counselling, about alcohol, drug, and cigarette use — both individually and through group sessions such as support groups.
- Many people that have a drug addiction also have a mental health problem or a psychiatric illness, and this condition must be treated concurrently with the substance abuse (see Module 6).
- Although it is the role of healthcare workers to impart knowledge, skills, and to reinforce a sound values base in relation to health and drug use, healthcare workers should not accept sole responsibility for reducing a client's drug or alcohol use. Whenever possible, healthcare workers should involve parents and caregivers, community-based and

youth-focused organisations, and the wider community, such as schools.

- Everyone responds in their own way to treatment and what may work for one person, may not work for another.



### Trainer Instructions

Slides 56-61

**Step 16:** Facilitate Exercise 1, which will give participants a chance to work through case studies highlighting different aspects of positive living.

<b>Exercise 1: Supporting ALHIV to Live Positively: Case studies and large group discussion</b>	
<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To work through case studies that will help participants think about how to best handle challenging situations with adolescent clients</li> </ul>
<b>Duration</b>	30 minutes
<b>Advance Preparation</b>	<ul style="list-style-type: none"> <li>• Review the case studies and make any adjustments to reflect the local situation.</li> </ul>
<b>Introduction</b>	Adolescent clients come to the clinic with many different types of problems (related to their home lives, school, friends, health, etc.). This exercise will go through case studies as a group to help participants think through how they might handle some common, challenging situations.
<b>Activities</b>	<p><b>Large Group Discussion</b></p> <ol style="list-style-type: none"> <li>1. Ask for a volunteer to read the first case study out loud.</li> <li>2. Facilitate a discussion about the case study, asking participants: <ul style="list-style-type: none"> <li>• <i>How will you assess the major issues?</i></li> <li>• <i>What questions would you ask the client and/or caregiver?</i></li> <li>• <i>What else would you want to know?</i></li> <li>• <i>Would you do any assessments to get more information?</i></li> <li>• <i>How would you counsel the client? What are some of the key “positive living” points that you should make for this client?</i></li> <li>• <i>What would the next steps be?</i></li> </ul> </li> <li>3. (optional) Ask the adolescent co-trainer if he or she would like to share any personal experiences related to the case study or any additional comments.</li> <li>4. Follow the same steps for the 3 remaining case studies.</li> <li>5. If any time remains at the end of this exercise, ask for volunteers to role play the case study of their choice in front of the large group.</li> </ol>

<b>Debriefing</b>	<ul style="list-style-type: none"> <li>• Working with adolescent clients can be challenging. As healthcare workers, we have to be prepared to deal with very complicated and difficult situations that may not have any easy answers.</li> <li>• This is why it is especially important to be aware of all the resources available to clients in the clinic and surrounding communities. By linking clients with several resources, healthcare workers can help clients get the support they may not be able to get from the health facility.</li> </ul>
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**Exercise 1: Supporting ALHIV to Live Positively: Case studies and large group discussion**

**Case Study 1:**  
 During a routine visit, Annie, a 16-year-old young woman, tells you that she has been feeling sad a lot lately and hardly ever feels hungry anymore. You also notice that she does not appear to have bathed in several days. She tells you that she has been living with HIV her whole life, and isn't sure what is causing her to feel so down. How would you proceed with Annie?

**Key points for trainers: Annie**

- Start by reassuring Annie that your discussion today, as always, is confidential.
- As discussed in Module 6, you might want to start with an “Assessment of Well Being” (see Table 6.1), which may lead to screening for depression (see “Appendix 6B: Screening and Management Tool for Depression”), depending on how she responds to the questions. The “Assessment of Well Being” includes questions about her support network, but you might want to enquire further about friendships, changes in friendships, boyfriends and peer support. Be sure to refer her to a peer support group.
- It doesn't seem that substance abuse is an issue here, but you will know more after administering the “Assessment of Well Being”.
- There are a couple of positive living points that need to be discussed with Annie:
  - It is important for her to eat regularly. Find out a bit more about why she is not eating regularly; is it just due to a lack of appetite? Or is she experiencing symptoms (for example, sore throat) that make it difficult to eat? Is the family experiencing food insecurity? She should be eating at least 3 meals a day along with at least 1 healthy snack/day. Her diet should include foods for all 3 food groups. Sometimes eating can help you feel hungry. Discuss some of the other suggestions for “Loss of Appetite” in “Appendix 9D: Nutritional Management of Common Symptoms Related to Advanced HIV Infection”.
  - Ask her when she last bathed. If it was several days ago, ask her if she'd like to talk about this a bit more. Presumably this is not

typical for Annie, so praise her for her good personal hygiene in the past, discuss the importance of bathing daily and ask her if she is willing/able to return to her daily bathing routine.

- Provide referrals and make an appointment for a follow-up visit.

### **Case Study 2:**

When you ask Katib, a 14-year-old boy, about his diet, he tells you that both of his parents are having trouble finding work and that there is rarely enough food to eat at home. Most days, they only have nshima, and sometimes there is money to buy chips or biscuits from the shop. How would you proceed with Katib?

#### **Key points for trainers: Katib**

- Do not forget to use the routine “Assessment of Well Being” (see Table 6.1) with Katib, to get a full picture of key issues since his last visit. If it appears that this primary issue is lack of food security in the home, then tell him that you would like to meet with his parents privately.
- If Katib has other personal issues, discuss those first, then tell him that you would now like to meet with his parents privately.
- In the meeting with Katib’s parents, find out a bit more about their job situation. Discuss gardening and small animal husbandry (for example, can they afford to buy a couple of chickens, can they borrow money to buy a couple of chickens and then sell the eggs to pay the loan back?). Have they considered re-locating to a village where they might have family support and land for subsistence farming? Discuss affordable foods; explore where to buy food cheaply. Find out what they are eating in addition to nshima (encourage them to make affordable, nutritious side dishes with beans, groundnuts, and vegetables), find out what they are putting in their nshima (would they consider adding soya, millet or sorghum flours to the maize when available?). Find out if they are well enough to cook and have access to energy (charcoal/ wood) and to safe water.
- Provide referrals and make an appointment for a follow-up visit.

### **Case Study 3:**

When Louis, a 17-year-old young man, comes in for his appointment, he has come with his mother. She pulls you aside before the visit and tells you that she is very concerned that Louis is spending many evenings out drinking with his friends. She is worried that he is damaging his health and may not be adhering to his medications. How would you proceed with Louis and his mother?

### **Key points for trainers: Louis**

- Meet with Louis individually (without his mother). Start by reassuring Louis that your discussion today, as always is confidential.
- As discussed in Module 6, you might want to start with an “Assessment of Well Being” (see Table 6.1), which will probably lead you to a screening for alcohol and maybe also substance abuse (“Appendix 9E: Screening and Management of Alcohol Dependency” and “Appendix 9F: Screening and Management of Drug Abuse”). The “Assessment of Well Being” may even suggest screening for depression (depression maybe the underlying reason he is drinking heavily).
- If Louis has a problem with alcohol use, as we suspect, go through the bullet points in part 3 (“Give feedback about the results of the screening, provide support and referrals”) of the screening tool. Agree on a plan for next steps.
- Discuss safer sex and give Louis condoms. Ask Louis if he has a partner. If so, find out what form of contraception she is using.
- Let Louis know that his mother is very concerned and that you need to provide her with some feed back on what we’ve discussed right now. Agree with Louis exactly what you can tell his mother.
- There are a couple of positive living points that need to be discussed with Louis:
  - Alcohol misuse can and does damage the health; this is particularly true for people with HIV.
  - If alcohol misuse leads to forgetting to take your ART, then a decline in health is not far behind. But this decline is not inevitable, if he can start taking his ARVs regularly.
- Provide referrals and make an appointment for a follow-up visit.

### **Case Study 4:**

Estelle is a 16-year-old who recently found out that she has HIV. She comes to the clinic every month but is always quiet. One of the Peer Educators mentioned that they saw her hanging out with some older men outside a store. She was smoking a cigarette and sharing some beer. How will you talk to her about positive living when she comes for her next clinic visit?

### **Key points for trainers: Estelle**

- Start by reassuring Estelle that your discussion today, as always is confidential.
- As discussed in Module 6, you might want to start with an “Assessment of Well Being” (see Table 6.1) to get Estelle to start talking. The assessment may or may not lead you to further screening (for depression, anxiety or substance abuse).
- If the assessment does not encourage her to talk about hanging out,

then ask her what she does in her free time. If she talks about her “friends”, ask about the ages and gender of these “friends”. Try to get her to talk about what she does and why she is doing it (is she exchanging sex for money or affection?). If necessary, confront her in a way that is positive and non-threatening by asking: “The Peer Educator saw you on Cairo Road, so what were you doing? Were you having fun? How long have you been hanging out with these men?”

- Ask about her relationship with her family and peers. Try to understand the underlying reasons for her decision to hang out. Enquire if the men are giving her money, if so discuss alternative ways to earn money.
- There are a couple of positive living points that need to be discussed with Estelle:
  - Let her know that moderate drinking is fine. But anything more than moderate (more than a glass or two a day) is not only expensive but is not good for your long term health.
  - Discuss safer sex, condom use, and how to negotiate safer sex with older, more powerful men. Ensure she is using contraception and give her condoms.
  - Ensure her relationship with these men is not violent.
  - Ask her about friends her own age, she if she’ll agree to spending more time with people her own age and either stop seeing these older men or at least spending less time with them.
  - Ask what made her start smoking. Be curious and supportive with your questions. Was she trying to fit in at school? Making an attempt to feel more grown-up? Discuss with her the expense of cigarettes and how else that money could be spent (electronics, clothes, etc). Appeal to her sense of vanity by reminding her that not only is smoking bad for your lungs, it also causes bad breath, yellowing of teeth and fingernails, and wrinkles.
  - If she is hanging out with these men instead of going to school, then discuss the importance of re-enrolling in school and getting her diploma.
- Provide referrals, such as to a peer support group and make an appointment for a follow-up visit.



### **Trainer Instructions**

Slides 62-63

- Step 17:** Facilitate Exercise 2, which will give participants a chance to practise planning and facilitating group sessions with ALHIV about positive living.

**Exercise 2: Planning a Presentation on Living Positively: Small group work and large group discussion**

<b>Purpose</b>	<ul style="list-style-type: none"> <li>To provide participants with practice planning and carrying out group sessions on positive living topics</li> </ul>
<b>Duration</b>	60 minutes
<b>Advance Preparation</b>	<ul style="list-style-type: none"> <li>None</li> </ul>
<b>Introduction</b>	Group sessions can be a useful way to educate and support ALHIV and their caregivers. As facilitators of such sessions, it is important that we choose topics and cover them in a way that will most benefit those participating in the group session.
<b>Activities</b>	<p><b>Small Group Work</b></p> <ol style="list-style-type: none"> <li>Break participants into 4 small groups. Give each group flip chart and markers.</li> <li>Assign each small group one of the following topics: <ul style="list-style-type: none"> <li>Keeping the mind healthy</li> <li>Keeping the body healthy</li> <li>Nutrition and hygiene</li> <li>Alcohol and drugs</li> </ul> </li> <li>Ask each small group to plan a health education session on their assigned topic for adolescent clients and their caregivers. Groups should assume they have 30 minutes to run the group session, making an outline of the topics and sub-topics they would plan to cover and writing the outline on flip chart.</li> <li>Once groups have finished writing the outline, they should choose one part of their outline and practise/role play how they would facilitate it and what they would actually say to a group of ALHIV and their caregivers. Each group should prepare a 5-minute segment to present to the large group.</li> </ol> <p><b>Large Group Work</b></p> <ol style="list-style-type: none"> <li>Bring the large group back together and ask each small group to present their agenda and the 5-minute excerpt they prepared. Participants not presenting should act as adolescents and caregivers in the audience and ask questions on the topic to simulate an actual group session.</li> <li>Following each small group presentation, the large group should comment on what went well and what could have been improved.</li> <li>(optional) Following each presentation, ask the adolescent co-trainer if he or she has any additional comments about the small group's outline or presentation.</li> </ol>

**Debriefing**

- Group sessions are a great way to educate many people at the same time, and are also a way to help clients share ideas and establish connections with one another.
- As healthcare workers, we should make sure to dedicate time to planning and regularly carrying out strong, well-run group sessions to help clients live positively with HIV.

**Trainer Instructions**

**Step 18:** Allow 5 minutes for questions and answers on this session.

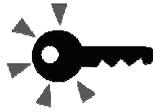
**Trainer Instructions**

Slides 64-67

**Step 19:** Ask participants what they think the key points of the module are. What information will they take away from this module?

**Step 20:** Summarise the key points of the module using participant feedback and the content below.

**Step 21:** Ask if there are any questions or clarifications



## **Module 9: Key Points**

- Although adolescents have to ultimately reach within themselves to ensure their minds are healthy, healthcare workers can do much to assist adolescents to find emotional and psychosocial health. Healthcare workers should routinely address positive living with their adolescent clients. As ALHIV develop and age, so does their need for information about keeping healthy. Examples of healthy living include using condoms and another family planning method, attending routine healthcare, taking prescribed medicines exactly as recommended, staying active, making friends, getting rest, eating healthy and exercising regularly.
- The relationship between nutrition and HIV is cyclical. It starts with HIV increasing nutrient requirements and reducing nutrient intake and absorption. This, in turn, increases the risk of malnutrition. Then malnutrition increases the risk of opportunistic infections and speeds the progression of HIV to AIDS. Conversely, good nutrition can strengthen the immune system, delay or prevent OIs, increase quality and length of life.
- ALHIV should eat a well-balanced diet that includes a variety of fresh foods from all three of the food groups. ALHIV will notice that they will need to eat more (perhaps an additional snack or additional meal every day) just to keep from losing weight.
- Healthcare workers need to monitor nutritional and health status by weighing their adolescent clients at each visit, recording their weight in the patient chart, and looking for and asking about changes.
- Helping adolescents learn about the risks of drugs, alcohol, and cigarettes before they start using them helps prevent addiction and harmful effects. This can be done through individual counselling and health education sessions and through group health education sessions with adolescents (and caregivers).
- Healthcare workers should watch for signs of alcohol misuse and abuse in their clients and screen for abuse. Those who are identified as abusing substances need education, counselling and referrals. Those identified at risk of substance abuse should be provided with support and referrals to address underlying issues (for example, social issues, depression, anxiety).

## **Appendix 9A: Web Resources for ALHIV**

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**Avert.org:** An online resource with easy to understand information on HIV transmission prevention, treatment, care, epidemiology, pathology, politics, and more. (<http://www.avert.org>)

**The Body:** An online HIV and AIDS resource with the mission to 1) Use the Web to lower barriers between patients and clinicians; 2) Demystify HIV/AIDS and its treatment; 3) Improve patients' quality of life; and 4) Foster community through human connection. ([www.thebody.com](http://www.thebody.com))

**Body and Soul Charity:** A UK-based organisation supporting people living with HIV. Its Teen Spirit section (for people living with HIV aged 13 and up) provides comprehensive information and resources geared specifically toward young people living with HIV. (<http://www.bodyandsoulcharity.org>)

**"Does HIV Look Like Me?"** A campaign, conceived of by YPLHIV from Hopes Voice International. It is an effort using mass media to target stigma, discrimination, and ignorance about the HIV and AIDS pandemic. Thus far 200 "ambassadors" — young people living with HIV — have participated in the campaign, using film, photography, and speaking opportunities in schools, churches, and community groups to raise awareness about HIV and people living with HIV. ([www.doeshivlooklikeme.org](http://www.doeshivlooklikeme.org))

**Go Ask Alice!** Columbia University's web portal for young people's questions about sex, sexuality, and more. (<http://www.goaskalice.columbia.edu>)

**Global Network of People Living with HIV and AIDS (GNP+):** An organisation with several regional networks working to improve the quality of life for all people living with HIV and AIDS. (<http://www.gnpplus.net>)

**Global Youth Coalition on HIV/AIDS (GYCA):** A youth-led global network of 5,000 young people working to end the spread of HIV in over 150 countries worldwide. GYCA prioritises 1) networking and sharing of best practices, 2) capacity building and technical assistance, 3) political advocacy, and 4) preparation for international conferences. Find other young people, mentors, donors, funders, scholarships, trainings and event opportunities related to HIV, AIDS and sexual reproductive health. ([www.youthaidscoalition.org](http://www.youthaidscoalition.org))

**Hopes Voice International:** A YPLHIV-led organisation committed to promoting the education and prevention of HIV and AIDS to young adults. Hope's Voice International aims to empower HIV positive youth to be leaders in educating their communities and be catalysts for change around

the globe. (<http://www.hopesvoice.org>)

**iAIDS.org:** A website for young people involved in the AIDS response with interactive tools and features. The results of the survey, respecting the privacy of anonymous responses, are available on the AIDS wiki website "iAIDS" designed by GYCA, TakingITGlobal, and UNICEF, as a resource for young people both infected and affected by HIV and AIDS as a collaborative space for information sharing and dialogue. ([http://wiki.iaids.org/en/Living\\_Positively](http://wiki.iaids.org/en/Living_Positively))

**International Community of Women Living with HIV (ICW):** A global community of women living with HIV. (<http://www.icw.org>)

**My Sex Life: Info for Poz Youth:** A youth-friendly, informative guide on safer sex and sexuality for YPLHIV, by the AIDS Committee of Toronto and Positive Youth Outreach, Canada. (<http://www.atoronto.ca/home.nsf/pages/mysexlife>)

**Youth R.I.S.E.:** An international youth network for reducing drug-related harm. (<http://youthrise.org/>).

Source: Global Youth Coalition on HIV/AIDS (GYCA). 2008. *Living Positively: Young People Living with HIV and the Health Sector Response* Available at: <http://www.youthaidscoalition.org/docs/livingpositively2008.pdf>

## Appendix 9B: Basic Food Groups

The basic food groups are as follows:

- **Energy giving (or “GO”) foods:** give us energy and make us **GO**. They include rice, maize, millet, sorghum, potatoes, sweet potatoes, bread, pasta, cassava and green bananas. These foods should make up the biggest part of each meal.
  - **Fats and sugars** can help give us energy, can help us gain weight, and can make foods taste better. However, they should be eaten with other healthy foods and in moderation. “Good fats” include things like avocados and groundnuts.
  - **Roughage, also known as fibre,** is important for the movement of the bowels and, therefore, helps to prevent constipation.
- **Body building (or “GROW”) foods** provide protein and help build our bodies and keep our muscles strong. They include meat, poultry, fish, offals, cheese, eggs, fresh and sour milk, beans, and groundnuts. Every meal should include at least 1 body building food. Note that ALHIV should try to eat legumes every day (for example, beans, lentils, peas, and nuts). They are usually cheaper than meat and provide a good source of protein.
- **Protective (or “GLOW”) foods** provide vitamins and minerals to help the immune system stay strong and fight off infections. They include all kinds of fruits and vegetables.

### Examples of energy giving, body building, and protective foods:

Energy giving foods (starches)	Body building foods (proteins and dairy)	Protective foods (fruits and vegetables)	
<ul style="list-style-type: none"> <li>• Nshima</li> <li>• Rice</li> <li>• Bread</li> <li>• Maize meal</li> <li>• Cassava</li> <li>• Yams</li> <li>• Millet</li> <li>• Sorghum</li> <li>• Potatoes</li> <li>• Crackers</li> </ul>	<ul style="list-style-type: none"> <li>• Beans</li> <li>• Lentils</li> <li>• Peas</li> <li>• Groundnuts</li> <li>• Sesame</li> <li>• Eggs</li> <li>• Fish</li> <li>• Beef</li> <li>• Lamb</li> <li>• Goat</li> <li>• Chicken</li> <li>• Pork</li> <li>• Milk</li> <li>• Yogurt</li> <li>• Cheese</li> <li>• Sour milk</li> <li>• Kapenta</li> </ul>	<ul style="list-style-type: none"> <li>• Bondwe</li> <li>• Carrots</li> <li>• Cabbage</li> <li>• Tomatoes</li> <li>• Okra</li> <li>• Spinach, leafy greens</li> <li>• Sweet potato and cassava leaves</li> <li>• Pumpkin leaves</li> <li>• Eggplant</li> <li>• Mushrooms</li> <li>• Cauliflower</li> <li>• Capsicum/peppers</li> </ul>	<ul style="list-style-type: none"> <li>• Avocadoes</li> <li>• Pineapple</li> <li>• Mango</li> <li>• Oranges</li> <li>• Lemons/limes</li> <li>• Pawpaw</li> <li>• Bananas</li> <li>• Pears</li> <li>• Peaches</li> <li>• Apples</li> <li>• Watermelon</li> <li>• Passion fruit</li> <li>• Guavas</li> <li>• Masuku</li> </ul>

## Appendix 9C: Key Components of a Nutritional Assessment

Measures	Interpreting results and next steps
<b>Anthropomorphic Assessment</b>	
<b>Weight and Height</b>	<ul style="list-style-type: none"> <li>• In patients who have lost 10% of body weight or 6–7 kg in a month: Assess ART eligibility</li> <li>• If loss &gt;5% of body weight over two to three months associated with OIs: Treat underlying conditions</li> <li>• If loss of &gt;10% of body weight over two to three months associated wasting syndrome (WHO Stage 4): Start ART.</li> </ul>
<b>BMI = Weight (Kg) / Height (M<sup>2</sup>)</b> <ul style="list-style-type: none"> <li>• BMI 18.5–24.9: Normal weight</li> <li>• BMI 25–29.5: Overweight</li> <li>• BMI 30 and above: Obese</li> </ul> (Does not apply to pregnant women)	<ul style="list-style-type: none"> <li>• If BMI &lt;18.5: Provide counselling and supply therapeutic food supplements</li> <li>• If BMI &gt;30: Recommend weight loss without compromising nutrition status</li> </ul>
<b>MUAC</b> (mid-upper arm circumference) Recommended for adolescents and adults who cannot stand up for weight and height measurements and for pregnant women	<b>Adults</b> <ul style="list-style-type: none"> <li>• &lt;16 cm: Severe malnutrition</li> <li>• 16–18.5 cm: Moderate malnutrition</li> </ul> <b>Pregnant Women</b> <ul style="list-style-type: none"> <li>• &lt; 17 cm: Severe malnutrition</li> <li>• 17–21.9 cm: Moderate malnutrition</li> </ul>
<b>Clinical assessment: what to look for</b>	
<ul style="list-style-type: none"> <li>• GI problems (diarrhoea, nausea, vomiting)</li> <li>• OIs that may interfere with food intake and absorption</li> <li>• Concurrent medical conditions (diabetes, hypertension, lipid problems)</li> <li>• Medication profile (medications taken, side effects that may affect food intake or absorption)</li> </ul>	
<b>Dietary assessment: what to ask about</b>	
<ul style="list-style-type: none"> <li>• Eating patterns, food regularly consumed, and frequency of meals</li> <li>• What foods are available and affordable</li> <li>• Food intolerance, allergies, and aversions</li> <li>• Dietary problems (for example, poor appetite, difficulty chewing and swallowing)</li> <li>• Food preparation and handling practices</li> <li>• Psychological factors that may contribute to inadequate food intake (for example, depression)</li> <li>• Physical activity</li> <li>• Use of mineral or vitamin supplements</li> <li>• Living environment and functional status</li> </ul>	

Measures	Interpreting results and next steps
<b>Biochemical assessment</b> <i>(where available)</i>	
What to test for or evaluate	Next steps
<ul style="list-style-type: none"> <li>• Serum albumin and/or proteins</li> </ul>	<ul style="list-style-type: none"> <li>• If low serum albumin: Advise a high protein diet</li> </ul>
<ul style="list-style-type: none"> <li>• Micronutrient deficiencies (for example, anaemia)</li> </ul>	<ul style="list-style-type: none"> <li>• If haemoglobin (Hb) &lt; 10: Advise diet high in iron and folic acid</li> <li>• If abnormal blood glucose: Profile for diabetes</li> </ul>
<ul style="list-style-type: none"> <li>• Glucose and lipid profile</li> </ul>	<ul style="list-style-type: none"> <li>• If abnormal lipid profile: Do further clinical evaluation</li> </ul>

## Appendix 9D: Nutritional Management of Common Symptoms Related to Advanced HIV Infection

Sign/symptom	Nutritional recommendations and management
<p><b>Major weight loss</b> (sometimes called “wasting”)</p>	<ul style="list-style-type: none"> <li>• Eat small meals often. Try to include “body building” (protein) foods with each meal.</li> <li>• Eat snacks during the day if possible (such as groundnuts, boiled eggs, and avocados).</li> <li>• Eat more “energy giving” foods (like rice, nshima, bread, and porridge).</li> <li>• Eat more beans, lentils, peas, and groundnuts.</li> <li>• Try to eat more meat, fish, and eggs.</li> <li>• Use more fats and oils in food, especially “good fats” like avocados and nuts.</li> <li>• Eat more dairy foods (like milk and yogurt).</li> <li>• Add dry milk powder or pounded groundnuts to foods (like porridge and cereals).</li> <li>• Add sugar, honey, syrup, or fruit jam to foods.</li> <li>• Try to eat more of your favourite foods.</li> <li>• Adhere to your care and treatment plan, including ART.</li> <li>• ALHIV may experience changes in their body shape. This is a long-term side effect that can be caused by ART. Some ALHIV may develop more fat on their stomach, breasts, or other areas and lose fat in their face, arms, and legs. These side effects may be confused with weight gain or weight loss.</li> </ul>
<p><b>Anaemia</b> (due to lack of iron in the diet; can also be caused by malaria and hookworm infections)</p>	<ul style="list-style-type: none"> <li>• Try to eat more meat, legumes, fish, eggs, green leafy vegetables, dried fruits, and whole grains.</li> <li>• Do not drink coffee, tea, milk, or cocoa while eating — these reduce how the body processes iron.</li> <li>• Eat fruits and vegetables with lots of Vitamin C (such as oranges, lemons, and green leafy vegetables) to increase how the body processes iron.</li> <li>• Go to the health facility to treat malaria, hookworm, or other parasites.</li> <li>• Take a multivitamin with iron as well as iron tablets.</li> <li>• Adhere to your care and treatment plan, including ART.</li> </ul>
<p><b>Diarrhoea</b></p>	<ul style="list-style-type: none"> <li>• Eat soups and drink safe water, rice water, thin porridge, and weak tea to avoid dehydration.</li> <li>• Drink oral rehydration solution (ORS).</li> <li>• Eat small amounts of food many times a day.</li> <li>• Eat foods like millet, bananas, peas, and lentils to help retain fluids.</li> <li>• Eat foods like rice, bread, millet, maize, porridge, boiled potatoes, sweet potatoes, and crackers that are easy to digest.</li> </ul>

Sign/symptom	Nutritional recommendations and management
	<ul style="list-style-type: none"> <li>• Eat soft foods like bananas, squash, cooked and mashed green bananas, paw-paws, mashed sweet potatoes, and mashed carrots.</li> <li>• Eat eggs, chicken, or fish for protein.</li> <li>• Adhere to your care and treatment plan, including ART.</li> </ul> <p><b>Stay away from:</b></p> <ul style="list-style-type: none"> <li>• Strong citrus fruits (like oranges and lemons)</li> <li>• Dairy products, such as milk — try fermented products instead, like yogurt or sour milk</li> <li>• Caffeine (coffee and tea)</li> <li>• Alcohol</li> <li>• Fried foods</li> <li>• Very sugary foods</li> <li>• Extra oil, butter, or lard</li> <li>• Gas-forming foods (like cabbage, onions, and carbonated soft drinks)</li> </ul>
<b>Nausea and vomiting</b>	<ul style="list-style-type: none"> <li>• Drink fluids, especially clean water, to prevent dehydration.</li> <li>• Eat bland soups.</li> <li>• Eat fruit, such as bananas.</li> <li>• Eat lightly salty and dry foods, such as crackers or bread, to calm the stomach.</li> <li>• Drink herbal teas and lemon juice in hot water.</li> <li>• Eat small amounts of food many times a day.</li> <li>• Adhere to your care and treatment plan, including ART.</li> </ul> <p><b>Stay away from:</b></p> <ul style="list-style-type: none"> <li>• Spicy or fatty foods</li> <li>• Caffeine (coffee and tea)</li> <li>• Alcohol</li> </ul>
<b>Mouth and throat sores or infection</b>	<ul style="list-style-type: none"> <li>• Eat soft mashed foods, such as scrambled eggs, cooked carrots, sweet potatoes, bananas, soup, paw-paws, and porridge.</li> <li>• Eat cold foods or foods at room temperature.</li> <li>• Drink liquids, such as beef broth, lentil, or pea soup.</li> <li>• Rinse the mouth with clean, warm salt water before and after eating.</li> <li>• Use cinnamon tea as a mouthwash.</li> <li>• Suck on clean ice, if available, to relieve pain.</li> <li>• For thrush, eat fermented foods, such as plain yogurt and sour milk. Sucking on a lemon and eating garlic can also help.</li> <li>• See the nurse or the doctor, and adhere to your care and treatment plan, including ART.</li> </ul> <p><b>Stay away from:</b></p> <ul style="list-style-type: none"> <li>• Spicy or salty foods that can irritate mouth sores</li> <li>• Strong citrus fruits and juices that can irritate mouth sores</li> </ul>

Sign/symptom	Nutritional recommendations and management
	<ul style="list-style-type: none"> <li>• Sugary foods and drinks</li> <li>• Rough foods like toast and raw vegetables</li> <li>• Alcohol</li> </ul>
<b>Loss of appetite</b>	<ul style="list-style-type: none"> <li>• Eat small, frequent meals throughout the day.</li> <li>• Eat nutritious snacks between meals.</li> <li>• Take walks before meals if possible — fresh air helps to stimulate appetite.</li> <li>• Avoid smoking — it reduces appetite.</li> <li>• Add seasonings, especially herbs, to food to give it more flavour.</li> <li>• Try rinsing out the mouth after meals.</li> <li>• Use lemon, raw tomatoes, or tonic water to stimulate the taste buds.</li> <li>• Chew food well and move it around the mouth to stimulate taste buds.</li> <li>• Avoid strong-smelling foods.</li> <li>• Eat with others as much as possible.</li> <li>• Adhere to your care and treatment plan, including ART.</li> </ul>
<b>Taste changes</b> (can sometimes be caused by ARVs and other medications)	<ul style="list-style-type: none"> <li>• Change sweetness, saltiness, or sourness of food by adding sugar, salt, jam, or lemon to increase the taste.</li> <li>• Try different herbs and spices.</li> <li>• Eat more fish or chicken, as meat can often have a metallic taste.</li> <li>• Eat lentils, beans, or split peas.</li> <li>• Brush teeth after eating to remove any aftertaste.</li> <li>• Adhere to your care and treatment plan, including ART.</li> </ul>

**Sources:**

WHO/Food and Agriculture Organization (FAO). 2002. *Living well with HIV/AIDS: A manual on nutritional care and support for people living with HIV/AIDS*. Geneva, Switzerland: WHO/FAO.

Colton, T., Dillow, A., Hainsworth, G., Israel, E., & Kane, M. 2006. *Community home-based care for people and communities affected by HIV/AIDS: A comprehensive training course for community health workers*. Watertown, MA: Pathfinder International.

## Appendix 9E: Screening and Management of Alcohol Dependency

✓	<b>Screening and management of alcohol dependency</b>
	<b>1. Use the CAGE questionnaire</b>
	<ul style="list-style-type: none"> <li>• Have you ever felt that you should <b>C</b>ut down on your drinking?</li> <li>• Have people <b>A</b>nnoyed you by criticising your drinking?</li> <li>• Have you ever felt bad or <b>G</b>uilty about your drinking?</li> <li>• Have you ever had an <b>E</b>ye-opener — a drink first thing in the morning to steady your nerves or get rid of a hangover?</li> </ul>
	<b>2. If the client responded “yes” to 2 OR MORE of the above questions, then he or she may have alcohol dependency.</b>
	<b>3. Give feedback about the results of the screening, provide support and referrals.</b>
	<ul style="list-style-type: none"> <li>• Provide information about the hazards of drinking (including poor adherence to HIV care and treatment).</li> <li>• Involve the adolescent’s caregiver(s), if appropriate and if the adolescent gives consent.</li> <li>• Emphasize the benefits of changing, and assess the client’s level of motivation to change.</li> <li>• If the client wants to change drinking behaviour, discuss goals and provide advice and encouragement.</li> <li>• Provide referrals to a support group and for further counselling. If needed, find a facility that may be able to help the patient overcome physical dependency and, if necessary, detoxification to treat delirium tremens (severe alcohol withdrawal).</li> </ul>

Adapted from: Ewing , J.A. 1984. *Detecting Alcoholism: The CAGE Questionnaire*. Journal of the American Medical Association 252: 1905-1907.

## Appendix 9F: Screening and Management of Drug Abuse

✓	<b>Screening and management of drug abuse</b>
	<b>1. Use the DAST questionnaire. In the last 12 months:</b>
	1. Have you used drugs other than those required for medical reasons?
	2. Have you abused prescription drugs?
	3. Do you abuse more than 1 drug at a time?
	4. Can you get through the week without using drugs?
	5. Are you always able to stop using drugs when you want to?
	6. Have you had “blackouts” or “flashbacks” as a result of drug use?
	7. Do you ever feel bad or guilty about your drug use?
	8. Do your parents (or spouse) ever complain about your involvement with drugs?
	9. Has drug abuse created problems between you and your parents (or spouse)?
	10. Have you lost friends because of your use of drugs?
	11. Have you neglected your family because of your use of drugs?
	12. Have you been in trouble at work/school because of your use of drugs?
	13. Have you lost a job because of drug abuse?
	14. Have you gotten into fights when under the influence of drugs?
	15. Have you engaged in illegal activities in order to obtain drugs?
	16. Have you been arrested for possession of illegal drugs?
	17. Have you experienced withdrawal symptoms (felt sick) when you stopped taking drugs?
	18. Have you had medical problems as a result of your drug use (for example, memory loss, hepatitis, convulsions, bleeding, etc.)?
	19. Have you gone to anyone for help for a drug problem?
	20. Have you been involved in a treatment programme especially related to drug use?
	<b>2. Score the questionnaire as follows</b>
	<ul style="list-style-type: none"> <li>• Score 1 point for each “yes” response EXCEPT for the following two questions: <ul style="list-style-type: none"> <li>• <i>Can you get through the week without using drugs?</i></li> <li>• <i>Are you always able to stop using drugs when you want to?</i></li> </ul>           For these two questions, score 1 point for “no” responses) </li> <li>• <b>If the client’s score is 6 OR MORE, then he or she may have a substance use problem.</b></li> <li>• <b>If the client’s score is 16 OR MORE, this may indicate very severe substance abuse.</b></li> </ul>

<b>3. Give feedback about the results of the screening, provide support and referrals.</b>
<ul style="list-style-type: none"> <li>• Supply information about the hazards of drug use (including poor adherence to HIV care and treatment).</li> <li>• Involve the adolescent's caregiver(s), if appropriate and if the adolescent gives consent.</li> <li>• Emphasize the benefits of changing, and assess the client's level of motivation to change.</li> <li>• If the client wants to change his or her behaviour related to drug use, discuss goals and provide advice and encouragement.</li> <li>• Provide referrals to a support group and for further counselling. If needed, find a facility that may be able to help the patient overcome physical dependency and provide counselling and support.</li> </ul>

Adapted from: Gavin, D.R., Ross H.E., Skinner, H.A. 1989. *Diagnostic validity of the Drug Abuse Screening Test in the Assessment of DSM-III Drug Disorders*. British Journal of Addiction 84(3): 301-307.

## References and Resources

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<sup>1</sup> Republic of Zambia, Ministry of Health. 2008. *Paediatric HIV Care Training Course, 2008*.

<sup>2</sup> Zambia Ministry of Health, National Food and Nutrition Commission. 2004. *Nutrition Guidelines for Care and Support of People Living with HIV/AIDS*. Available at: [http://www.fantaproject.org/publications/zambia\\_guide2005.shtml](http://www.fantaproject.org/publications/zambia_guide2005.shtml)

<sup>3</sup> Program for Appropriate Technology in Health (PATH). 2006. *Tuko Pamoja Adolescent Reproductive Health and Life Skills Curriculum*.

<sup>4</sup> United Nations Children's Funds. 2006. *Life Skills – based Education for Drug Use Prevention Training Manual*. UNICEF.



# Module 10 Sexual and Reproductive Health Services for Adolescents



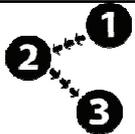
**Total Module Time:** 370 minutes (6 hours, 10 minutes)

## Learning Objectives

**After completing this module, participants will be able to:**

- Reflect on their own attitudes, values, and beliefs on adolescent sexuality and discuss how these may affect their work with adolescents.
- Define key terms related to sex, sexuality, sexual orientation, and sexual identity.
- Identify potential effects of HIV on sexuality among adolescents.
- Define safer sex and discuss how to empower adolescent clients to practise safer sex.
- Support adolescents to practise safer sex.
- Conduct sexual risk screening and sexual risk reduction counselling with adolescent clients.
- Explain the importance of and provide STI screening and treatment for adolescent clients.
- List ways to make SRH and other clinical examinations more adolescent-friendly.
- List the risks of adolescent pregnancy.
- Discuss childbearing choices and safe childbearing with adolescent clients.
- Understand adolescent-specific contraceptive issues and challenges.
- Counsel adolescent clients on prevention of mother-to-child transmission of HIV (PMTCT).

## Methodologies



- Interactive trainer presentation
- Large group discussion
- Brainstorming
- Case studies
- Role play
- Small group work

## Materials Needed



- Slide set for Module 10
- Flip chart and markers
- Tape or Bostik
- Participants should have their Participant Manuals. The



	Participant Manual contains background technical content and information for the exercises.
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### References and Resources



- Zambia Ministry of Health, Directorate of Public Health Research. 2010. *2010 National Protocol Guidelines — PMTCT.*
- Zambia Ministry of Health, *Family Planning Counselling Kit.*
- Zambia Ministry of Health, *National STI Syndromic Case Management Guidelines for Zambia.*
- Zambia Ministry of Health. 2008. *National Reproductive Health Policy.*
- WHO. 2010. *IMAI One-day orientation on Adolescents Living with HIV, Facilitator Guide.* Geneva, WHO Press.

### Advance Preparation



- Read through the entire module and ensure that all trainers are prepared and comfortable with the content and methodologies.
- Review the appendices in this module ahead of time and prepare to incorporate them into the discussion. Be sure to take time to read through the entire article in “Appendix 10A: Journal Article”
- All exercises require advance preparation. Please review each ahead of time.

### **Session 10.1: Values Clarification and Introduction**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation and large group discussion	15 minutes
Exercise 1: SRH Values Clarification: Large group exercise	25 minutes
Interactive trainer presentation and large group discussion	5 minutes
Questions and answers	5 minutes
<b>Total Session Time</b>	<b>50 minutes</b>

### **Session 10.2: Adolescent Sexuality**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation	5 minutes
Exercise 2: Key Terms about Sex, Sexuality, and Sexual Orientation: Small group work and large group discussion	20 minutes
Interactive trainer presentation and large group discussion	25 minutes
Exercise 3: OK For Me?: Large group exercise and discussion	25 minutes
Questions and answers	5 minutes
<b>Total Session Time</b>	<b>80 minutes</b>

### **Session 10.3: Supporting Adolescent Clients to Practise Safer Sex**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation, large group discussion, and brainstorming	30 minutes
Exercise 4: Condom Demonstration: Return demonstration and large group discussion	25 minutes
Interactive trainer presentation and large group discussion	15 minutes
Questions and answers	5 minutes
<b>Total Session Time</b>	<b>75 minutes</b>

### **Session 10.4: Integrating Sexual Risk Screening, Risk Reduction Counselling, and STI Services into Adolescent HIV Services**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation and large group discussion	45 minutes
Questions and answers	5 minutes
<b>Total Session Time</b>	<b>50 minutes</b>

### **Session 10.5: Providing Childbearing, Contraceptive, and PMTCT Counselling and Services to ALHIV**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation and large group discussion	40 minutes
Exercise 5: Providing SRH Services to Adolescent Clients: Case studies, role play, and large group discussion	60 minutes
Questions and answers	5 minutes
Review of key points	10 minutes
<b>Total Session Time</b>	<b>115 minutes</b>

## Session 10.1 Values Clarification and Introduction



**Total Session Time:** 50 minutes



### Trainer Instructions

Slides 1-4

**Step 1:** Begin by reviewing the Module 10 learning objectives and the session objective, listed below.

**Step 2:** Ask participants if there are any questions before moving on.

### Session Objective

**After completing this session, participants will be able to:**

- Reflect on their own attitudes, values, and beliefs on adolescent sexuality and discuss how these may affect their work with adolescents.

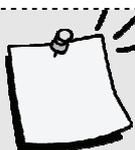


### Trainer Instructions

Slides 5-7

**Step 3:** Ask participants to share some of their own experiences related to adolescent sexual and reproductive health (SRH) among their clients.

**Step 4:** Give a short overview on the importance of integrating SRH services into care and treatment services for adolescents.



### Make These Points

- Sexuality and sexual activity often begin during adolescence.
- An important part of adolescent HIV care and treatment is assessing and responding to the SRH needs of clients. In order to do so, healthcare workers must be comfortable talking about sexuality and SRH with their clients, and knowledgeable about the common SRH issues adolescents are facing and the SRH services and information they need.
- This module provides participants with key information and skills needed to support adolescent clients' emerging sexuality and SRH.

## Introduction on Adolescent Sexuality

Sexuality emerges during adolescence and for many people, so does sexual activity. Healthcare workers should never assume that their adolescent clients are not sexually active. Instead, they should recognise that their adolescent clients are already or will be sexually active. It is important that all members of the multidisciplinary team feel comfortable talking about sexuality and sexual and reproductive health (SRH) with adolescents, and are able to offer adolescent clients non-judgemental sexual education and SRH counselling and services.



### Trainer Instructions

Slides 8-10

**Step 5:** Facilitate Exercise 1 to help participants explore their own attitudes and values related to adolescent sexuality. This exercise is run similar to “Exercise 3: Values clarification: Large group exercise” in Module 1.

<b>Exercise 1: SRH Values Clarification: Large group exercise</b>	
<b>Purpose</b>	<ul style="list-style-type: none"> <li>To help participants begin to think about their values, attitudes, and prejudices related to adolescent sexuality and SRH, and how these might affect their work with adolescent clients</li> </ul>
<b>Duration</b>	25 minutes
<b>Advance Preparation</b>	<ul style="list-style-type: none"> <li>Prepare 2 large flip chart papers, one that says, “AGREE” and another that says, “DISAGREE.”</li> </ul>
<b>Introduction</b>	This activity will help us begin to explore participants own values, attitudes, and prejudices related to adolescent sexuality and SRH.
<b>Activities</b>	<ol style="list-style-type: none"> <li>Post the prepared flip chart papers that say “AGREE” and “DISAGREE” on opposite sides of the training room. Ideally, they should be posted in an open space where participants are able to move back and forth between signs.</li> <li>Ask participants to stand up and move to the open space in the room where the “AGREE” and “DISAGREE” signs are posted. Tell participants that you will read some statements out loud and that, after each statement, they should move to the “AGREE” or the “DISAGREE sign, based on their opinions. If participants are not sure whether they agree or disagree with the statement, they can stand somewhere between the two signs.</li> <li>Read out load each of the sentences listed below. Allow participants a few seconds to move to the side of the room that reflects their opinion. Ask a few participants</li> </ol>

	<p>to tell the group why they “AGREE” or “DISAGREE” with the statement. Allow participants to change their answer after these explanations, if desired. Do not worry about explaining the “right” answers, as all of these topics will be discussed during this module.</p> <p>4. Once you have read all of the statements below, or 20 minutes have passed, ask participants to return to their seats.</p>
<p><b>Debriefing</b></p>	<p>Ask participants what they think is the point of this activity, note the following points:</p> <ul style="list-style-type: none"> <li>• It is important that all members of multidisciplinary teams caring for ALHIV think about the issues related to their own attitudes, values, and prejudices related to adolescent sexuality and how these could affect their ability to provide effective care and treatment services to adolescent clients.</li> <li>• It is also important that healthcare workers are sensitive to the emerging feelings of their adolescent clients, make them feel comfortable, and make them feel that it is “safe” to talk openly and honestly in the clinic setting.</li> </ul>

### **Statements for Values Clarification Exercise:**

1. Most parents are NOT comfortable talking with their adolescents about sex.
2. If a male client tells you he is sometimes attracted to other men, it is your job to discourage any homosexual behaviour.
3. Adolescents these days think about sex way too much.
4. HIV infection can have an affect on adolescents’ sexuality.
5. We should encourage adolescents living with HIV to remain abstinent for as long as possible.
6. It is wrong for an adolescent living with HIV not to disclose his status to his partner.
7. There are safe ways for adolescents living with HIV to be sexually active.
8. It is important that an adolescent’s parent or caregiver is present when a healthcare worker talks to him or her about sex.
9. It is best to refer adolescents to the STI clinic or the family planning clinic for these services instead of providing them in the care and treatment clinic.
10. Adolescents living with HIV who say they want to have children should be encouraged to wait.



#### **Trainer Instructions**

**Step 6:** Ask participants to turn to “Appendix 10A: Journal Article”. Recommend that they bookmark this article and review it this

evening, if they have time. Provide a very brief overview of the article, which discusses a study in Uganda undertaken to learn more about sexual behaviour and desires among ALHIV. Key points from the article include the following:

- Many ALHIV are sexually active, or desire to be in a sexually active relationship.
- Many adolescents may not be using condoms consistently or practising other prevention methods.
- Disclosure of HIV status to sexual partners can be challenging for adolescents and also has implications on sexual risk reduction.
- There is a great need to provide age- and situation-appropriate, and non-judgemental SRH information and services, going beyond the promotion of abstinence, to ALHIV.

**Step 7:** (optional) Ask the adolescent co-trainer to comment on the article and whether or not it reflects the realities among the adolescents in his or her community.



#### **Trainer Instructions**

**Step 8:** Allow 5 minutes for questions and answers on this session.

## Session 10.2 Adolescent Sexuality and HIV



**Total Session Time:** 80 minutes (1 hour, 20 minutes)



### Trainer Instructions

11-12

**Step 1:** Begin by reviewing the session objectives listed below.

**Step 2:** Ask participants if there are any questions before moving on.

### Session Objectives

**After completing this session, participants will be able to:**

- Define key terms related to sex, sexuality, sexual orientation, and sexual identity.
- Identify potential effects of HIV on sexuality among adolescents.



### Trainer Instructions

Slides 13-14

**Step 3:** Start the session by facilitating Exercise 2, which is an introduction to some of the key terms that will be used during this module.

### Exercise 2: Key Terms about Sex, Sexuality, and Sexual Orientation: Small group work and large group discussion

<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To provide participants with definitions for words used to describe sexual expression and sexual orientation</li> </ul>
<b>Duration</b>	20 minutes
<b>Advance Preparation</b>	<ul style="list-style-type: none"> <li>• Review the 21 terms in “Trainer Tools for Exercise 2: Word and Definition Cards” on page 83. Add any words (and their definitions) that are used locally to discuss sexual expression or orientation. Make one copy for each small group (so, if you have 20 participants and they will be breaking into groups of 3, then you will need 6 or 7 copies). Cut the pages along the dotted lines to make 42 (or more, if you have added some local terms) cards for each small group.</li> <li>• Write the following words/terms on flip chart paper. Write 3 or 4 words per sheet of flip chart, leaving enough space between words so that participants can write in definitions during the exercise. Make sure</li> </ul>

	<p>there are enough sheets of flip chart so that each group can fill in one.</p> <ul style="list-style-type: none"> <li>• Sex (verb)</li> <li>• Sex (noun)</li> <li>• Vaginal sex</li> <li>• Anal sex</li> <li>• Oral sex</li> <li>• Sexuality</li> <li>• Body image</li> <li>• Gender roles</li> <li>• Relationship</li> <li>• Intimacy</li> <li>• Love</li> <li>• Sexual arousal</li> <li>• Social roles</li> <li>• Genitals</li> <li>• Gender</li> <li>• Heterosexuality</li> <li>• Homosexuality</li> <li>• Bisexuality</li> <li>• Transvestism</li> <li>• Transsexual</li> <li>• Transgendered</li> </ul> <ul style="list-style-type: none"> <li>• Also include on the flip chart the local terms that you have added to your set of cards.</li> </ul>
<b>Introduction</b>	<p>This exercise is to help prepare participants to provide adolescent clients with SRH support and counselling. It is important that they understand the definitions of words commonly used to describe sexual expression and sexual orientation.</p>
<b>Activities</b>	<p><b>Small Group Work</b></p> <ol style="list-style-type: none"> <li>1. Ask participants to divide into small groups of about 3–4 people per group.</li> <li>2. Divide the prepared sets of cards (cut out from “Trainer Tools for Exercise 2: Word and Definition Cards”) so that each small group gets one full set of cards.</li> <li>3. Ask each group to match the word card with its correct definition card.</li> <li>4. Give each group 1 sheet of the flip chart paper on which you have written 3 or 4 of the words. Ask each group to fill in the definition for the words on their flip chart. When they have completed their assignments, collect the flip chart paper and post them on the wall.</li> </ol> <p><b>Large Group Discussion</b></p> <ol style="list-style-type: none"> <li>5. Ask the first group to give the definitions of the words listed on their sheet of flip chart. Ask the rest of the groups if they agree. If they do not agree, ask them what they think are the correct definitions.</li> <li>6. Then go onto the next group and ask them to define the words on their sheet of flip chart, repeat the same process until all of the words have been defined and everyone agrees on the definitions.</li> <li>7. Ask participants if they have any questions or comments before moving on, reassuring them that we will be discussing these ideas more during the rest of the session.</li> </ol>
<b>Debriefing</b>	<p>Ask participants how they felt discussing these terms; make the following points:</p> <ul style="list-style-type: none"> <li>• Even as healthcare workers, sometimes we find it difficult to talk about sex and sexuality. One of the objectives of this exercise was to give participants an opportunity to prove to themselves that they <i>can</i> talk</li> </ul>

	<p>about sex and sexuality comfortably within a professional context — this is the first step to initiating SRH discussions with clients.</p> <ul style="list-style-type: none"> <li>• Although some of these may be unfamiliar concepts, and in some cases may seem to go against the local culture and norms, as healthcare workers we must remember that our first priority is providing care and support to our clients. This means accepting their feelings and choices, and trying to never judge them or make them feel abnormal.</li> <li>• We will learn more about sexuality and sexual orientation in this session.</li> </ul>
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### Trainer Instructions

Slides 15-24

**Step 4:** Following Exercise 2, present the definitions of key terms describing sexuality and sexual orientation and identity, using the content below.

**Step 5:** Next ask participants:

- *What are some of the ways adolescents may express their sexuality?*
- *What challenges do you think adolescents may face with regard to expressing their sexuality?*
- *How can healthcare workers create a comfortable and accepting environment for adolescent clients?*

Note responses on flip chart. Fill in, as needed, from the content below.

**Step 6:** (optional) Ask the adolescent co-trainer to share his or her thoughts on the following:

- *How do you think adolescents express their sexuality?*
- *What are some of the challenges adolescents face around their emerging sexuality?*
- *How do you think healthcare workers can create a supportive and non-judgemental environment where adolescents feel more comfortable discussing their sexuality?*



### Make These Points

- **Sex** (as a verb) usually refers to vaginal, anal, or oral sex with another person or alone (masturbation). **Unsafe sex** is any kind of sex that puts a person at risk of a sexually transmitted infection or unplanned

pregnancy. Whereas **sexuality** includes all the feelings, thoughts, and behaviours of being a girl or boy, including being attractive, being in love, and being in relationships.

- Healthcare workers need to stress that homosexual, bisexual, and transsexual/transgendered behaviour is **NORMAL** (regardless of the healthcare worker's personal views).
- Healthcare workers do not have to be experts on sexual orientation and sexual identities. A willingness to listen, be understanding, and refer adolescent clients to resources is often enough.
- However, it is important that healthcare workers learn as much as they can about sexuality, sexual orientation, and sexual identify so they can become more comfortable with the feelings and behaviours they will likely see among their adolescent clients. The more comfortable healthcare workers feel discussing these issues, the more support they will be able to provide to their adolescent clients.

## **Sex and Sexuality**

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### **Sex (as a verb):**

Sex can be a normal part of life for many older adolescents and adults. Sex means different things to different people, including:

- Vaginal sex (when the penis or fingers go into the vagina)
- Anal sex (when the penis or fingers go into the anus)
- Oral sex (when a person kisses or licks their partner's penis, vagina, or anus)
- Inserting fingers or objects into the vagina or anus
- Masturbation (alone or with a partner)
- Having sex with men, women, or both men and women.

Sex as a verb is also referred to as "intercourse" or "sexual intercourse".

### **Unsafe sex**

- HIV is mainly spread to adolescents and adults through **unsafe sex**. **Unsafe sex** is any kind of sex that puts a person, or his or her sexual partners, at risk of getting a sexually transmitted infection, including HIV, or unwanted pregnancy.
- It is very important for healthcare workers to be comfortable talking about sex and reproduction with their adolescent clients. Frank, factual discussions about sex and sexuality can provide adolescents with the information they need to protect themselves and their partners from sexually transmitted infection and unplanned pregnancy.

### **Sexuality:**

- Is more than sex and sexual feelings.
- Includes all the feelings, thoughts, and behaviours of being a girl or boy, including being attractive, being in love, and being in relationships that include sexual intimacy and physical sexual activity.

- Exists throughout a person's life and is a component of the total expression of who we are as human beings, male or female.
- Is constantly evolving as we grow and develop.
- Is a part of us from birth to death.

## Sexuality: Key Terms

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The following are some aspects of sexuality. Each of these aspects is connected to each other and makes a person who he or she is.

- **Body image:** How we look and feel about ourselves, and how we appear to others
- **Gender roles:** The way we express being either male or female, and the expectations people have for us based on our sex
- **Relationships:** The ways we interact with others and express our feelings for others
- **Intimacy:** Sharing thoughts or feelings in a close relationship, with or without physical closeness
- **Love:** Feelings of affection and how we express those feelings for others
- **Sexual arousal:** The different things that excite us sexually.
- **Social roles:** How we contribute to and fit into society
- **Genitals:** The parts of our bodies that define our sex (male or female). They are part of sexual pleasure and reproduction
- **Ways we can express sexuality:** dancing, talking with other sex, wearing attractive clothes, sexual dreams, feeling sexual near others, masturbation, daydreams, and others

### Remember:

- In many places, “sex” is often thought to mean only penis-vagina sex between a man and a woman. But sexual behaviours include much more than penis-vagina sex.
- If healthcare workers do not talk about sex and sexual behaviours with clients, they may not get the information, skills, and supplies they need to protect themselves and their partners and reduce risks of HIV, STIs, sexual violence, discrimination, and unplanned pregnancy.
- While we all hold our own opinions about different sexual behaviours, as healthcare workers, we cannot project our own values on clients. Adolescent clients should always be made to feel comfortable talking about their sexual concerns, questions, and behaviours without risk of judgement.

## Sexual Orientation and Identity

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- Adolescence is a time of sexual experimentation and of defining one's sexual identity.
- Healthcare workers need to stress that homosexual, bisexual, and transsexual/transgendered behaviour is NORMAL (regardless of the healthcare worker's personal views).

- Adolescence is a period of change, and an adolescent’s sexual identity may not be his or her permanent identity.
- However, adolescence is a period when sexual identity starts to be defined. An adolescent who realises that he or she may be gay, bisexual, or transgendered may feel isolated and depressed. It is the healthcare worker’s responsibility to help the adolescent cope with his or her sexual orientation and accept him- or herself.
- The healthcare worker does not have to be an expert on sexual orientation. The most important thing is that the healthcare worker be willing to listen to adolescent clients in a non-judgemental way, and to provide referrals if necessary.

### **Creating a gay-friendly atmosphere**

Although most adolescents are heterosexual, some will have a different sexual orientation such as homosexual or bisexual. Adolescents who are not heterosexual are particularly vulnerable. They may experience profound isolation and fear of discovery. They are more likely to experience harassment and violence and are at higher risk of dropping out of school, being kicked out of their homes, and experimenting with tobacco, alcohol, and illegal drugs at an earlier age. It is important that healthcare workers ensure that homosexual and bisexual youth know that they will not be judged and that they are welcome in the clinic. Healthcare workers are obligated to ensure that all youth — regardless of sexual orientation — feel comfortable and are provided with the care, treatment, and support that they need, including safer sex counselling. If clinic staff do not feel qualified to counsel gay youth about homosexuality, they should know where to refer for peer support.

## **Sexual Orientation and Identity: Key Terms**

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- **Sex (as a noun):** Refers to the physiological attributes that identify a person as male or female (genital organs, predominant hormones, ability to produce sperm or ova, ability to give birth, etc.).
- **Gender:** Refers to widely shared ideas and norms about women and men, including common beliefs about what characteristics and behaviour are “feminine” or “masculine.” Gender reflects and influences the different roles, the social status, as well as the economic and political power of women and men in society.
- **Heterosexuality:** The sexual orientation in which a person is physically attracted to people of the opposite sex.
- **Homosexuality:** The sexual orientation in which a person is physically attracted to people of the same sex.
- **Bisexuality:** The sexual orientation in which a person is physically attracted to members of both sexes.
- **Transvestism:** When a person dresses and acts like a person of the opposite gender.

- **Transsexual:** A person who desires to change, or has changed, his or her biological sex because his or her body does not correspond to his or her gender identity.
- **Transgendered:** A person who lives as the gender opposite to his or her anatomical sex (for example, a male living as a female but retaining his penis and sexual functioning).



### Trainer Instructions

Slides 25-29

**Step 7:** Explain to participants that HIV can affect the emerging sexuality of ALHIV.

**Step 8:** Ask participants:

- *In what way do you think HIV might affect the sexuality of adolescent clients?*
- *In what ways might this differ for perinatally-infected adolescents and adolescents who acquire HIV later in life?*

Fill in using the content below.

**Step 9:** Provide an overview of sexual abuse. Start by asking:

- *Has anyone dealt with an adolescent client who was sexually abused?*
- *If so, how did you handle it?*

Fill in using the content below. Refer participants to “Appendix 10B: Adolescent Sexual Abuse”. If participants are interested in this topic, and you have time, include the content of Appendix 10B in your presentation.

**Step 10:** (optional) Ask the adolescent co-trainer to comment on the ways he or she thinks living with HIV effects adolescents’ sexuality.



### Make These Points

- HIV can have both psychological and physical effects on ALHIV’s sexuality.
- HIV can affect the emerging sexuality of adolescents in several ways, including worsening the body image and self-esteem of adolescent clients.
- It is important that healthcare workers understand these potential effects, as well as the extreme importance for adolescents to feel like

they “fit in” and are “normal”.

- Sexual abuse is defined as forcing unwanted, improper or harmful sexual activity on another. If an adolescent indicates that he or she has been a victim of sexual abuse, healthcare workers need to take this disclosure seriously, encourage further disclosure, provide counselling and referrals and where necessary, provide legal follow up.

## **Effects of HIV on Sexuality Among ALHIV**

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- ALHIV may have lower self-esteem than their peers.
- Approaching puberty, adolescents become preoccupied with their developing bodies and body image.
- Adolescents compare their bodies to those of their peers of the same sex. They have an intense need to “fit in.”
- Adolescents wonder and worry about their level of sexual attractiveness.
- The effects of HIV can result in adolescent clients having increased anxiety about sexuality, sexual relationships, and reproductive and sexual functions.
- ALHIV often have concerns about if/how they can have sexually intimate relationships and fears around disclosure to sexual partners and HIV transmission to sexual partners.
- ALHIV may have concerns and questions about being able to have safe sexual relationships and children in the future.
- Not ‘fitting in’ can be very traumatic for adolescents, especially when it involves ‘looking different.’
- ALHIV, especially those perinatally infected and those who went a long time without HIV treatment, may begin puberty later and grow and develop more slowly than their HIV-uninfected peers.
- ALHIV are subject to many illnesses, conditions, and drug side effects that may affect the way they look (for example, lipodystrophy, wasting, skin conditions, stunting or short stature). These body characteristics and changes may affect an adolescent’s body and self-image.
- Adolescents who acquired HIV through sexual abuse may harbour unresolved issues from the trauma related to the abuse (see next section).

## **Sexual Abuse<sup>1</sup>**

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Sexual abuse is defined as forcing unwanted, improper or harmful sexual activity on another. Many victims of sexual abuse are adolescents. Research in many countries has documented sexual abuse (ranging from harassment to rape and incest) among 7–34% of girls and 3–29% of boys.

Recognising sexual abuse can be a difficult task and one that is rarely straightforward. Identifying sexual abuse in young people requires careful investigation and assessment because very few signs and symptoms are

conclusive of sexual abuse. Often, there is no physical evidence that an adolescent has been sexually abused; changes in behaviour are far more common.

The most reliable and most common indicator of sexual abuse is an adolescent’s disclosure. When adolescents report that they are being or have been sexually abused, there is a high probability that they are telling the truth. Only in rare circumstances do adolescents have any interest in making false accusations. Sexual abuse — signs and symptoms of abuse, interviewing an adolescent who may have been abused, and follow up — is further discussed in “Appendix 10B: Adolescent Sexual Abuse” on page 67.

Zambia policy recommends the use of a multidisciplinary team approach in cases of sexual abuse among youth. The team should consist of at least 3 people and, when possible, include a representative from law enforcement, social welfare, and a healthcare worker. The purpose of the multidisciplinary team is to ensure that the physical, mental, and social support needs of the adolescent and family are met through a coordinated effort, thereby reducing the burden and distress faced by the adolescent.



### Trainer Instructions

Slides 30-31

**Step 11:** Facilitate Exercise 3, which helps participants further understand how their own values and attitudes about sexual behaviour may impact the adolescents that they serve.

<b>Exercise 3: OK For Me?: Large group exercise and discussion</b>	
<b>Purpose</b>	<ul style="list-style-type: none"> <li>To allow participants to examine their own values about sexual behaviours and discuss how these values and attitudes can affect the services provided to adolescents</li> </ul>
<b>Duration</b>	25 minutes
<b>Advance Preparation</b>	<ul style="list-style-type: none"> <li>Review the cards in “Trainer Tools for Exercise 3: Sexual Behaviour Cards” which starts on page 89. You may add other behaviours or omit some behaviours depending on local context. It is important to include some behaviours that are “outside of the mainstream” or taboo.</li> <li>Make enough copies of “Trainer Tools for Exercise 3: Sexual Behaviour Cards” so that each participant will have about 10 behaviour cards. Cut out the cards, by cutting along the dashed borders.</li> <li>Prepare sheets of flip chart paper, each with one of the following labels: “OK FOR ME,” “NOT OK FOR ME, BUT OK FOR OTHERS,” and “NOT OK”. Post the flip chart pages on the wall of the training room.</li> </ul>

<b>Introduction</b>	In this exercise, participants will be exploring a range of sexual behaviours and their own values and attitudes about those behaviours. Answers will be kept confidential. Encourage participants to be as honest and open as possible.
<b>Activities</b>	<p><b>Individual Work</b></p> <ol style="list-style-type: none"> <li>1. Give each participant 9 or 10 of the prepared behaviour cards. It is fine if they end up with duplicates.</li> <li>2. Ask participants to read each sexual behaviour card to themselves and decide how they feel about each behaviour, circling one of the options on the card (this behaviour is “OK for me,” “Not OK for me, but OK for others,” or “Not OK”).</li> <li>3. Remind participants that their answers will be kept confidential, so they should respond honestly. Also remind participants that this exercise is NOT about HIV risk, but about our values around sexual behaviours.</li> <li>4. Give participants about 3–4 minutes to circle their answer on each card and ask them to place them face down in a pile (or in an empty envelope) in the centre of the room.</li> <li>5. Mix up the cards and then divvy up the cards between several volunteers who will quickly sort the cards according to circled response: “OK FOR ME,” “NOT OK FOR ME, BUT OK FOR OTHERS,” and “NOT OK.” The cards should then be posted on the corresponding flip chart page using tape, Blu-Tack, or some other means.</li> </ol> <p><b>Large Group Discussion</b></p> <ol style="list-style-type: none"> <li>6. Once all of the cards have been posted, ask participants to gather around the flip chart pages and review the placement of the cards.</li> <li>7. Lead a group discussion using these questions as a guide: <ul style="list-style-type: none"> <li>• <i>Are you surprised by the placement of some of the cards? Which ones surprised you?</i></li> <li>• <i>Does the placement of the cards suggest that some sexual behaviours are “right” and some are “wrong?” How do you feel about that?</i></li> <li>• <i>Are there behaviours that are not OK under any circumstances (examples could include incest, rape, etc.)?</i></li> <li>• <i>What does this activity tell us about how adolescent clients might feel when we ask them about their sexual behaviours?</i></li> <li>• <i>How can we make our adolescent clients feel more comfortable talking about their sexual preferences and behaviours in the clinic?</i></li> </ul> </li> </ol>

<b>Debriefing</b>	<ul style="list-style-type: none"> <li>• While we all carry our own values and attitudes about sexual behaviours, it is important that healthcare workers be able to accept and talk about sex and sexuality openly and comfortably with adolescent clients.</li> <li>• Being open, non-judgemental, and truthful about sexuality makes it easier for adolescent clients to accept themselves and reduce their risk.</li> </ul>



**Trainer Instructions**

**Step 12:** Allow 5 minutes for questions and answers on this session.

## Session 10.3 Supporting Adolescent Clients to Practise Safe Sex



**Total Session Time:** 75 minutes (1 hour, 15 minutes)



### Trainer Instructions

Slides 32-33

- Step 1:** Begin by reviewing the session objectives listed below.
- Step 2:** Ask participants if there are any questions before moving on.

### Session Objectives

**After completing this session, participants will be able to:**

- Define safer sex and discuss how to empower adolescent clients to practise safer sex.
- Support adolescents to practise safer sex.



### Trainer Instructions

Slides 34-38

- Step 3:** Tell participants that now we are going to talk about sexual activity and risk of HIV. To get discussion going, ask:
- *How is HIV transmitted from one person to another during sexual activity?*
- Step 4:** Post 4 sheets of flip chart at the front of the room. One should be labelled “NO RISK,” another “LOW RISK,” the third “MEDIUM RISK,” and the fourth “HIGH RISK.” Ask for 4 volunteers to stand next to each flip chart and take notes.
- Read from the lists of behaviours below (not in order) and ask participants to decide how risky each activity is in terms of spreading/getting HIV and other STIs. Where there is a question about a particular activity, ask participants:
- *Which 4 body fluids transmit HIV?*
  - *Which body fluid is present during this activity?*
  - *Is there enough of this fluid to transmit HIV?*
  - *Is there a way for this fluid to get into the partner’s bloodstream?*
  - *As such, is this activity no, low, medium or high risk?*

Once an activity is categorised correctly, ask a volunteer to record that activity on the corresponding flip chart page.

**Step 5:** (optional) Ask the adolescent co-trainer to comment on the ways adolescents view the risk of different sexual behaviours, why he or she thinks adolescents participate in sexual behaviours that they know are risky, and what healthcare workers can do to help adolescents assess and lower their sexual risk-taking.



### **Make These Points**

- HIV is transmitted from one person to another through 4 body fluids: semen, vaginal secretions, blood, and breast milk.
- Sexual activities that present no risk of transmission are those during which no body fluids are exchanged, examples include hugging, kissing, massaging, and masturbation.
- A low risk sexual activity is when 1 of the 4 body fluids is present but does not get on or in the partner. A medium risk activity is when a person has contact with 1 of the 4 body fluids, but the body fluid does not enter the partners' body.
- A high risk sexual activity is when 1 or more of the 4 body fluids enters the body of another person, for example, unprotected (no male or female condom) anal or vaginal sex.

## **Understanding Risk**

HIV is transmitted from one person to another through four body fluids: semen, vaginal secretions, blood, and breast milk. Any activity during which one or more of these body fluids is passed from one person to another could pose a theoretical risk of HIV transmission if:

- The body fluid is from a person infected with HIV.
- The body fluid enters the bloodstream of another person, typically through a cut or abrasion, less often through mucous membranes.

Given the mechanism by which HIV is transmitted from one person to another, sexual activities that present no risk of transmission are those during which no body fluids are exchanged. Sexual activities that present a risk involve semen, vaginal secretions, blood or breast milk.

### **No risk:**

There are many ways to share sexual feelings that are not risky. These include:

- Hugging

- Kissing (Assuming there is no blood present in the mouth, even “French” kissing carries no risk of HIV transmission.)
- Holding hands
- Massaging
- Bathing or showering together
- Rubbing against each other with clothes on
- Sharing fantasies
- Self-masturbation
- Mutual masturbation

### **Low risk:**

- Masturbating your partner or masturbating together, as long as males do not ejaculate near any opening or broken skin of their partner
- Using a male or female latex condom for **every** act of sexual intercourse (penis in vagina, penis in anus, penis in mouth, etc.)
- Using a barrier method for oral sex on a male or female, or for any mouth to genitals or mouth to anus contact

### **Medium risk:**

- Sharing sexual toys (rubber penis, vibrators) without cleaning them
- Oral sex without a latex barrier (some STIs, like gonorrhoea, are easily passed through oral sex while others, like Chlamydia, are not. The risk of HIV transmission through oral sex is generally low, but there is some risk, especially if the person has an STI or cuts/sores in the mouth or on the genitals)

### **High risk:**

- Unprotected (no male or female condom) anal or vaginal sex



#### **Trainer Instructions**

Slides 39-45

**Step 6:** Ask participants to define the phrase “safer sex.” Record responses on flip chart and fill in, as needed.

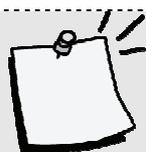
**Step 7:** Ask participants to discuss the following questions:

- *Are male and female condoms currently offered to ALL adolescent clients at your clinic? Why or why not?*
- *Are male and female condoms available in a private space in the waiting area, so adolescent clients do not have to ask for them?*
- *What have been your experiences discussing and demonstrating condom use with adolescent clients? What is challenging?*
- *What are some of the reasons you think adolescent clients do not use condoms? What can we do about this as healthcare workers?*

- *What can we do to make sure that ALL adolescent clients have access to condoms and the skills and knowledge to use them?*

**Step 8:** (optional) Ask the adolescent co-trainer to give his or her opinion on why adolescents may or may not use condoms consistently and what can be done to make it easier for adolescents to get and use condoms.

**Step 9:** Ask if anyone can define the term “dual protection” and record responses on flip chart. Fill in using the content below.



### **Make These Points**

- Safer sex describes the range of sexual activities that do not transmit STIs (including HIV) and protect against unintended pregnancy but are still pleasurable. Safer sex includes sexual practices during which body fluids are not passed between partners.
- Using condoms is a reliable way to practise safer sex and prevent STIs, HIV and unwanted pregnancy. For people who are living with HIV, condoms also prevent re-infection.
- ALHIV should have free and easy access to condoms in the clinic setting. They should not have to ask healthcare workers for condoms; instead they should be available in waiting areas, clinic rooms, and other places where young people can access them. Healthcare workers must remove barriers to condom use.
- Dual protection refers to the prevention of STIs, HIV, and unwanted pregnancy at the same time.

## **What Do We Mean by “Safer Sex?”**

**Safer sex** includes the range of ways that people can protect themselves and their partner(s) from HIV (or HIV “re-infection”), STIs, and unintended pregnancy.

- Safer sex involves choosing sexual practices and protection methods that prevent body fluids from passing from one person to another.
- Safer sex reduces these risks without reducing intimacy or pleasure.
- Safer sex includes the activities listed under “No risk:” (on page 21) and “Low risk:” (on page 22).

### **More on condoms:**

- Not having sex at all, known as abstinence, is one way to be completely safe. But for some adolescents this may not be practical. For people who are sexually active, using condoms is a reliable way to prevent STIs, HIV and unwanted pregnancy.
- There are a lot of myths about condoms, such as that they are only for sex workers or promiscuous people. Healthcare workers should

promote condoms for young people as a way of protecting themselves and their partners from HIV and other STIs.

- Some people feel that condoms make sex less enjoyable. Healthcare workers should respect everyone’s personal experiences with condoms, but reframe condoms as part of pleasurable foreplay and sex with condoms as relieving the worry about an unplanned pregnancy or guilt related to risking HIV transmission.
- Some people think that if both partners are living with HIV, then they do not need to use condoms. It is important for healthcare workers to explain that even if both partners are living with HIV, they should still use condoms to reduce the risk of transmitting new strains of HIV. This is particularly risky if the strain of HIV transmitted is resistant to the ART regimens used in Zambia. Condoms can also prevent the spread of other STIs and prevent unintended pregnancy.
- Some healthcare workers may think that giving young people condoms is equated to encouraging sex — but this is not true! It is important that male and female condoms are available and offered to adolescent clients in multiple settings — in the clinic waiting area, in examination rooms, in the lab, in the pharmacy, by Peer Educators, etc. Healthcare workers must remove as many barriers to condom use among adolescents as possible.

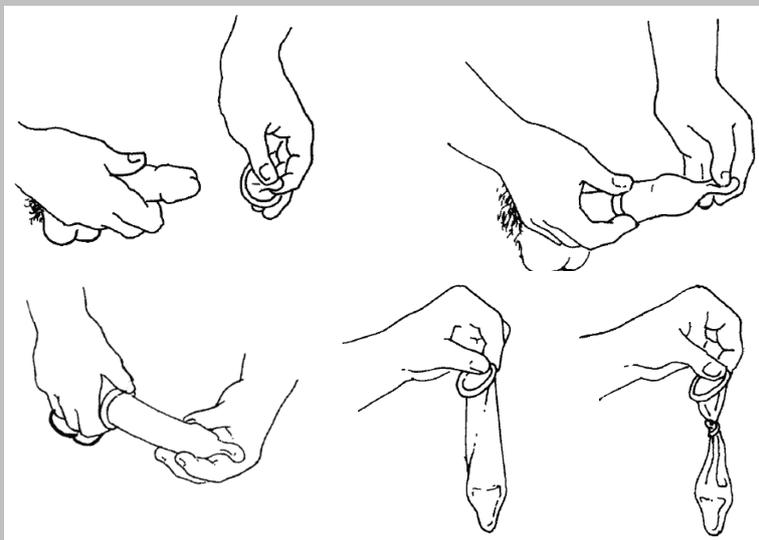
### **Dual protection:**

Dual protection means preventing STIs, HIV, and unwanted pregnancy at the same time. Various strategies offer dual protection, including abstinence and the “no risk” and “low risk” activities listed above. Other strategies include:

- Being in a monogamous relationship in which both partners are free of STIs and at least one partner is using effective contraception
- Using male or female condoms
- Using male or female condoms to protect against STIs and a second method to protect against unplanned pregnancy (often a hormonal method)

## How to use a male condom

These are the basic steps you should know for using and demonstrating how to use a male condom. If penis models are not available, you can use a bottle, banana, or corn. Only condoms made out of latex protect against HIV.



### Steps to use a male condom:

- Look at the condom package and check the expiry date to make sure it is still good and that the package is not damaged.
- Open the packet on one side and take the condom out. Do not use your teeth to open the package.
- Pinch the tip of the condom to keep a little space at the tip. This will hold the semen and prevent the condom from breaking.
- Hold the condom so that the tip is facing up and it can be rolled down the penis. (Make sure it is not inside out!)
- Put it on the tip of an erect (hard) penis (only use condoms on an erect penis) and unroll it down to the bottom of the penis.
- After ejaculation (coming), the rim of the condom should be held while the man removes his penis without spilling the semen. The penis must be removed while it is still hard to make sure the condom does not fall off.
- Remove the condom and tie it in a knot to avoid spilling. Throw it away in a latrine or bury it. Do not put it in a flush toilet.

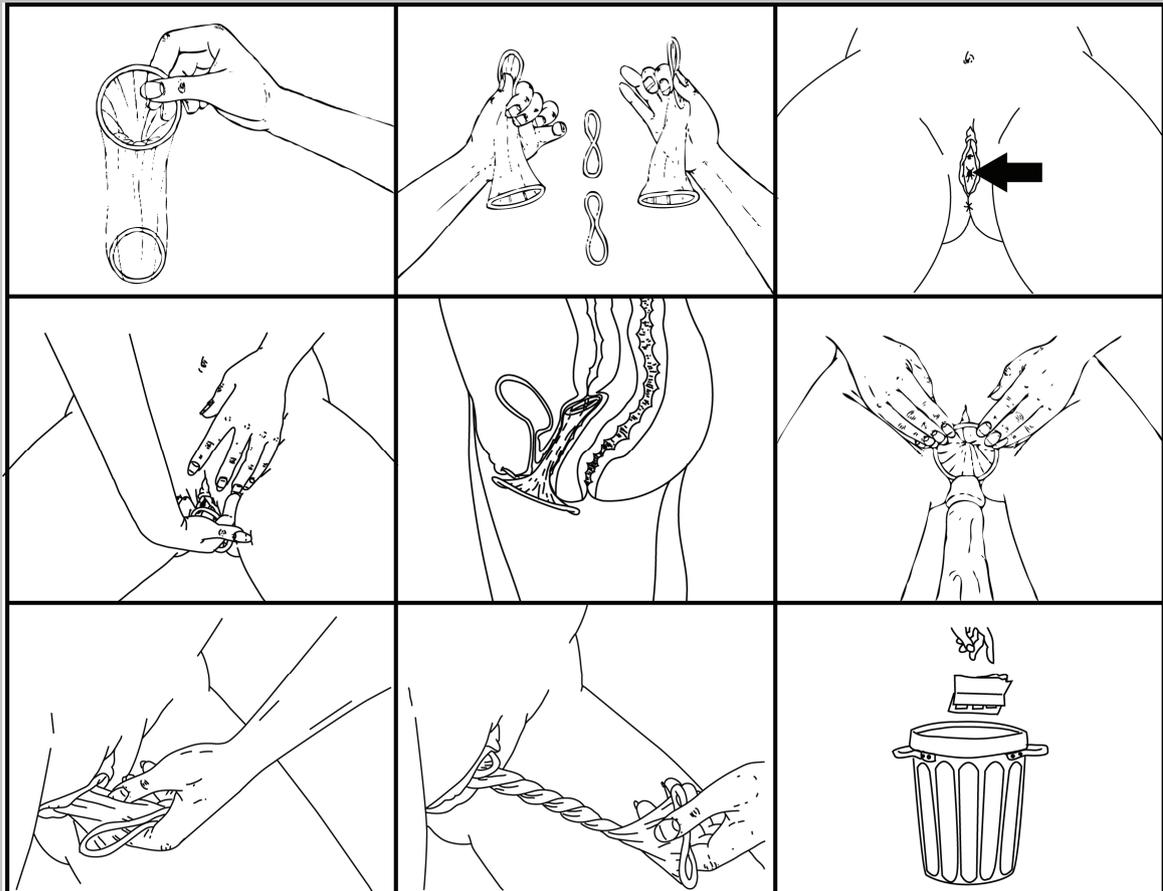
### Also, it is important to:

- Use a condom every time you have sex — oral sex, anal sex, or vaginal. Use a new condom every time! Never reuse a condom!
- Use only lubricants made out of water, not oils.
- Store condoms in a cool, dry place, out of the sun. Do not keep them in a wallet.
- Do not use condoms that seem to be sticky, a strange colour or damaged in any way. Throw them away.

Adapted from: Burns, A., Lovich, R., Maxwell, J., & Shapiro, K. 1997. *Where women have no doctor: A health guide for women*. Berkeley, CA: The Hesperian Foundation.

## How to use a female condom

Some women like the female condom because it gives them more control over their own bodies and over sex. Some men like it, too, because they do not have to use a male condom. The female condom is becoming more affordable and available. These are the main steps for using a female condom. If no vaginal model is available to demonstrate its use, you can use a box with a round hole cut in it or your hand.



### Steps to use a female condom:

- Look at the condom package to make sure it is not damaged and check the expiry date to make sure it is still good.
- Open the packet. Do not use your teeth.
- Find the inner ring at the closed end of the condom. The inner ring is not attached to the condom.
- Squeeze the inner ring between the thumb and middle finger.
- Guide the inner ring all the way into the vagina with your fingers. The outer ring stays outside the vagina and covers the lips of the vagina.
- When you have sex, guide the penis through the outer ring so that the penis is inserted into the female condom.
- After the man ejaculates (comes), before the woman stands up, squeeze and twist the outer ring to keep the semen inside the pouch and pull the pouch out.
- Put the used condom in a latrine or bury it. Do not put it in a flush toilet.

Adapted from: Burns, A., Lovich, R., Maxwell, J., & Shapiro, K. 1997. *Where women have no doctor: A health guide for women*. Berkeley, CA: The Hesperian Foundation.



### Trainer Instructions

Slides 46

**Step 10:** Facilitate Exercise 4, which provides an opportunity for participants to practise demonstrating male and female condom use.

#### Exercise 4: Condom Demonstration: Return demonstration and large group discussion

<b>Purpose</b>	<ul style="list-style-type: none"> <li>To help participants feel comfortable demonstrating how to put on a male and female condom</li> </ul>
<b>Duration</b>	25 minutes
<b>Advance Preparation</b>	<ul style="list-style-type: none"> <li>Make sure to have enough male and female condoms for each participant, as well as penis and vagina models.</li> </ul>
<b>Introduction</b>	Most healthcare workers know how to use condoms, but it is important to be comfortable demonstrating both male and female condom use to adolescent clients.
<b>Activities</b>	<p><b>Large Group Demonstration — male condom</b></p> <ol style="list-style-type: none"> <li>1. Ask if anyone is willing to demonstrate to the entire group how to put on a male condom, using a penis model (or a substitute for a penis model, such as a banana, cob of corn or bottle). Ensure that each step is explained in simple, adolescent-friendly language. After the volunteer (or the trainer, if there was no volunteer) demonstrates, then ask the group how they thought the demonstration went, providing corrections if there were any mistakes.</li> </ol> <p><b>Return Demonstration</b></p> <ol style="list-style-type: none"> <li>2. Ask participants to get into pairs and take turns demonstrating how to put on a male condom on a penis model, as if they were doing such a demonstration with an adolescent in the clinic. Make sure participants explain each step correctly.</li> </ol> <p><b>Large Group Demonstration — female condom</b></p> <ol style="list-style-type: none"> <li>3. Ask if anyone can demonstrate to the entire group how to insert a female condom into a vagina model. The demonstrator should explain each step. Again, after the volunteer (or the trainer, if there was no volunteer) demonstrates, then ask the group how they thought the demonstration went, providing corrections if there were any mistakes.</li> </ol>

	<p><b>Return Demonstration</b></p> <p>4. Ask participants to form new pairs and take turns demonstrating to each other how to insert the female condom into a vagina model, as if they were doing such a demonstration with an adolescent in the clinic. Make sure participants explain each step correctly.</p> <p><b>Large Group Discussion</b></p> <p>5. Bring the large group back together and ask participants how they felt demonstrating how to put on a male condom and how to insert the female condom. Then ask why healthcare workers sometimes feel uncomfortable demonstrating condom use to adolescent clients.</p>
<p><b>Debriefing</b></p>	<ul style="list-style-type: none"> <li>• Explain that it is important for healthcare workers to provide condoms and demonstrate how they are used.</li> <li>• It is also important that healthcare workers support adolescent clients to use condoms by teaching them how to negotiate safer sex and respond to common questions or complaints that they, or their partners, may have about condoms.</li> <li>• Even if a healthcare worker doesn't think a client is sexually active, it is still good to prepare them with the facts, including how condoms can prevent HIV transmission, re-infection, STIs, and unintended pregnancy.</li> <li>• Even though it can be hard and embarrassing for adolescents AND healthcare workers to talk about condoms, condoms are a very important part of comprehensive care for ALHIV.</li> <li>• Condoms (male and female) should be available in many locations at the clinic — in the waiting room, in exam rooms, in bathrooms, in the lab, in the pharmacy, and with Peer Educators. The more available condoms are, the more adolescents are likely to take them and use them!</li> </ul>



**Trainer Instructions**

Slides 47-55

**Step 11:**

Even though we know *how* to practise safer sex, many people still do not have safer sex. Lead a discussion on some of the most common reasons adolescents do not practise safer sex, using the following questions as a guide:

- *What are some of the reasons adolescents may not practise safer sex?*
- *Do you think there are specific reasons ALHIV may not practise safer sex, despite the risks? Explain.*
- *What do you think healthcare workers can do to help*

adolescent clients assess their sexual risks and practise safer sex?

- Step 12:** (optional) Ask the adolescent co-trainer to share his or her thoughts on the reasons adolescents do not practise safer sex and what can be done by healthcare workers to support adolescents to make safe sexual decisions.



### Make These Points

- There are many reasons that people — including adolescents — do not practise safer sex:
  - Ignorance: lack of information about the risks of HIV infection or re-infection and pregnancy; lack of information about safer sex and contraceptive methods including condoms
  - Denial: not wanting to plan ahead or refusing to believe the risks
  - Lack of access to condoms and other methods of family planning
  - Coercion, particularly if one partner want to get pregnant
  - Fear and embarrassment: fear of rejection, fear of the unknown, embarrassment of buying condoms (or another family planning method) or asking the partner to use them

## Reasons Why Adolescents May Not Practise Safer Sex<sup>2</sup>

### Ignorance:

- They think they are not vulnerable to HIV, HIV re-infection, pregnancy, or STIs. “*It cannot happen to me*” or “*I do not have sex often enough to get pregnant.*”
- They do not have adequate or accurate information about safer sex:
  - Many adults are embarrassed to talk about sex with adolescents, or they may not have the facts themselves.
  - Some adults believe that adolescents should not be having sex.
  - School sex education is often inadequate or non-existent.
  - Parents and other adults are reluctant to provide practical information. Some believe that providing information encourages sexual activity, though this has been proven to be untrue.
  - The media portrays sexuality unrealistically and usually does not include any mention of protection.
- They have heard misinformation or myths about methods and their side effects.
- They do not know that methods are available or which methods can be used by ALHIV.
- They do not know where, how, or when to get condoms or other contraceptive methods.

- They do not know how to correctly use condoms.
- Myths about dangers of contraception are common and difficult to defuse.
- They are not aware of pleasurable alternatives to risky sex, such as mutual masturbation, etc.

### **Denial:**

- “*Sex just happened.*” (They did not expect to have sex).
- “*I only had sex once.*”
- “*Sex should be spontaneous.*”
- “*My friends are not using protection, so why should I?*”
- They don’t think they will get pregnant or an STI, or think that there is only a small chance of passing HIV during sex.

### **Lack of access:**

- Access to contraceptive services for adolescents is limited by law, custom, or clinic/institutional policy.
- Availability and cost may restrict access.
- Irregular supply of methods available.
- Sex happened spontaneously — method not available when needed.
- Healthcare worker attitudes towards contraception may prevent them from distributing protective methods to adolescents.

### **Coercion:**

- One of the partners wants to get pregnant.
- One of the partners will not let the other use protection.
- One of the partners forces the other to have sex.
- They have the attitude that condoms ruin sex or are unromantic.
- There is pressure from their family to conceive.

### **“What the heck” effect:**

- ALHIV may feel that because they are already HIV-infected, there is no need to protect themselves. This might be especially true if both sexual partners are HIV-infected.
- ALHIV may be depressed and have lost hope — thinking “What the heck, I already have HIV so why not take risks?”

### **Fear:**

- Fear of rejection by partner.
- Fear of people knowing HIV status if they use condoms/request partner to use condoms.
- Fear of the lack of confidentiality at the place methods can be obtained.
- Fear of using something new — fear of the unknown.
- Fear of side effects.
- Fear about the proper use of protective methods.
- Fear of where to keep protective methods so that no one sees them.

- Fear that something may go wrong if they start using certain contraceptive methods, like oral contraceptive pills, too early in life.
- Fear that their parents will find out they are having or planning to have sex.
- Fear that their peers or parents will know they are sexually active.
- Fear of being asked questions by a pharmacist or healthcare worker if they request condoms or contraceptive methods.
- Fear of being labelled as “cheap” or “loose”.

### **Embarrassment:**

- Service providers and pharmacists are sometimes judgemental and/or moralistic about adolescent sexual activity. This is especially true for ALHIV — as many people think it is irresponsible for people living with HIV to have sex at all.
- They are embarrassed to buy condoms.
- Retail outlets often place contraceptive methods behind the counter so that customers have to ask for them.
- They are embarrassed to suggest using condoms in the “heat of the moment”.

### **Other factors:**

- They lack the skill and expertise to negotiate condom use.
- They stopped using oral contraceptives because of the side effects.
- They are impulsive and sexual activity is often unplanned. Even when sex is anticipated, they often do not have protection available.
- They believe that the suggestion of protection implies mistrust of one’s partner and his or her faithfulness.
- They desire conception. For a girl, it may be a way to keep a relationship or a boyfriend; for a boy, conception may be a way to prove manhood; or they may be married.
- They lack the communication and negotiation skill to discuss protection.
- They think their partner “is taking care of protection.”
- They have not made a firm decision about whether or not they would like to get pregnant.
- They do not know how to dispose of condoms or do not have a place to dispose of them properly and privately.



### **Trainer Instructions**

**Step 13:** Allow 5 minutes for questions and answers on this session.

## Session 10.4      Integrating Sexual Risk Screening, Risk Reduction Counselling, and STI Services into Adolescent HIV Services

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**Total Session Time:**      50 minutes



### **Trainer Instructions**

Slides 56-57

- Step 1:**      Begin by reviewing the session objectives listed below.
- Step 2:**      Ask participants if there are any questions before moving on.

### **Session Objectives**

**After completing this session, participants will be able to:**

- Conduct sexual risk screening and sexual risk reduction counselling with adolescent clients.
- Explain the importance of and provide STI screening and treatment for adolescent clients.
- List ways to make SRH and other clinical examinations more adolescent-friendly.



### **Trainer Instructions**

Slides 58-59

- Step 3:**      Explain to participants that despite the many factors that can result in adolescents engaging in risky sexual activity, healthcare workers can ensure they are well-informed and empowered to take steps to reduce risky behaviour, maintain sexual and reproductive health, while also preventing new HIV infections.
- Step 4:**      Ask participants, including the adolescent co-trainer, to brainstorm what is meant by the phrase “positive prevention.” Record answers on flip chart and lead a discussion about the importance of positive prevention as an integral part of adolescent HIV care and treatment services.



### Make These Points

- Healthcare workers have an important role in supporting adolescent clients to practise positive prevention. Healthcare workers are responsible for providing accurate information about HIV and STIs; responding to questions about sexuality, future childbearing, disclosure and transmission risk.
- SRH support and counselling must be provided in a non-judgemental manner.

## Positive Prevention

Although information alone cannot be expected to change the sexual behaviour of adolescents, healthcare workers can help adolescent clients understand the transmission risk of certain activities and provide guidance to help them reduce risky behaviour, have good sexual and reproductive health, and prevent new HIV infections. This is called **positive prevention**. See Module 9 (Session 9.2) for more information on positive prevention.

Adolescent clients need access to accurate information about HIV and STI transmission to address their concerns about sexuality, dating, future childbearing, disclosure, and transmission risk. In general, adolescents want their healthcare provider(s) to give accurate information and to sensitively ask them personal questions about HIV-related risk behaviour — without judgement and ensuring confidentiality.

In order for these discussions to be effective, adolescent clients must feel that their providers will comfortably and supportively engage in dialogue with them about any topic — no matter how uncomfortable it may be. Young people can sense when healthcare workers are out of their element or passing judgement discussing sensitive issues and this perception will likely prevent honest communication about risk behaviours.



### Trainer Instructions

Slides 60-63

- Step 5:** Provide an overview of the sexual risk screening process. Then provide an overview of the sexual risk screening and risk reduction counselling discussion. Fill in using the content below.
- Step 6:** Ask participants:
- *How do you currently conduct sexual risk screening and risk reduction counselling with adolescent clients?*
  - *What questions do you ask to screen for sexual risk?*
  - *What questions do you ask when counselling on risk*

*reduction?*

- *What are some of the challenges of sexual risk screening and risk reduction counselling?*

Review Table 10.1 and Table 10.2.

**Step 7:** (optional) Ask the adolescent co-trainer to comment on ways he or she thinks healthcare workers can make adolescents comfortable talking about sexual risk and open to risk reduction counselling.



### **Make These Points**

- Sexual risk screening starts before a client is sexually active.
- The sexual risk screening includes questions to help the healthcare worker assess if the client is sexually active, if so, with whom and what risks is he or she taking.
- Risk reduction counselling focuses on reducing risk of HIV, STIs and unwanted pregnancy by helping the client choose a strategy that is right for him or her. Strategies can include abstinence, partner reduction, and condom use. The counselling session also includes information about early treatment of STIs, adherence to ARV regimen, and disclosure.

## **Sexual Risk Screening and Counselling**

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### **The process:**

- Start asking routine screening questions as early as possible with adolescent clients.
- Build trust with clients:
  - Start to address sexuality before the client becomes sexually active.
  - Begin with safer topics, such as physical changes of puberty. Educate the client and caregivers about what to expect in terms of sexual, physical, emotional, and social development during puberty and adolescence.
  - When meeting with caregivers, begin by exploring their expectations about their child's sexual activity and then use these expectations to begin providing guidance to both caregivers and the adolescent client.
- By the time they are 12 years old, see adolescent clients separately from their caregiver for at least part of each appointment.

### **Overview of the discussion:**

- Explain to adolescent clients and caregivers what information can and cannot be kept confidential, emphasizing that healthcare workers will

protect their confidentiality, unless there is an emergency or there is a health risk requiring intervention.

- Use good communication and counselling skills (see Module 4).
- Avoid making assumptions about the client, including the client's knowledge, behaviour, sexual orientation, etc.
- Always ask about sexual behaviour rather than sexual identity.
- Avoid using any labels not first used by the client.
- If a discussion is awkward, respect a client's clues that further talk is unwanted.
- The elements of a sexual risk screening are in Table 10.1.
- The risk reduction counselling session, which would follow the sexual risk screening, is summarised in Table 10.2.

**Table 10.1: Sexual risk screening**

✓	Questions for client
<b>1. Is client sexually active?</b>	
	<ul style="list-style-type: none"> <li>• <i>Some adolescents have sex with their partners. Are you having sex?</i></li> </ul> If the response is "no" go to Table 10.2. If "yes" proceed to section 2 of this table.
<b>2. If yes, with whom?</b>	
	<ul style="list-style-type: none"> <li>• <i>Are you having sex with men, women, or both?</i></li> <li>• <i>How many partners do you have or have you had?</i></li> <li>• <i>What is the HIV status of your partner(s)?</i></li> <li>• <i>Which of your partners knows you have HIV?</i></li> </ul>
<b>3. What?</b>	
	<ul style="list-style-type: none"> <li>• <i>Do you have vaginal sex? Oral sex? Anal sex?</i></li> <li>• <i>What family planning method did you use the last time you had sex?</i></li> <li>• <i>When was the last time you used a condom?</i></li> <li>• <i>Has anyone caused you harm in the past; for example, hurt you physically or unwanted sexual encounters?</i></li> <li>• <i>How often in the last week have you used cigarettes, alcohol, or other drugs?</i></li> </ul>

**Table 10.2: Risk reduction counselling**

✓	Questions for client
<b>1. Assess knowledge</b>	
	<ul style="list-style-type: none"> <li>• <i>How is HIV transmitted?</i></li> <li>• <i>How is sexual transmission of HIV prevented?</i></li> <li>• <i>What is your plan for preventing sexual transmission of HIV?</i></li> <li>• <i>Did you know that even people with HIV should practise safer sex? Do you know why? (Response: to reduce risk of acquiring resistant virus.)</i></li> </ul>
<b>2. Discuss options for sexual risk reduction</b>	

	<ul style="list-style-type: none"> <li>• <i>There are a number of ways to reduce risk of HIV, other STIs and unwanted pregnancy, including:</i> <ul style="list-style-type: none"> <li>• <i>Abstinence</i></li> <li>• <i>Intimate touching without exchange of bodily fluids</i></li> <li>• <i>Reducing number of partners</i></li> <li>• <i>Disclosing status and negotiating sexual practices</i></li> <li>• <i>Correctly and consistently using condoms</i></li> <li>• <i>STI screening and treatment (HIV is transmitted more easily in the presence of other STIs).</i></li> <li>• <i>Maintaining maximal suppression of HIV through excellent adherence to ART, if eligible</i></li> <li>• <i>Avoiding alcohol, marijuana, party drugs, and other substances that impair good judgement and prevention</i></li> </ul> </li> </ul>
<b>3. If an option, discuss abstinence</b>	
	<ul style="list-style-type: none"> <li>• <i>Abstinence means not having sex, if you are abstinent you cannot get (re-infected with) HIV, STIs or have an unplanned pregnancy.</i></li> <li>• <i>Is abstinence an option for you?</i></li> <li>• <i>If you choose abstinence, you should have a back up plan as well, just in case you change your mind. What will be your back up plan?</i></li> </ul>
<b>4. Discuss condoms</b>	
	<ul style="list-style-type: none"> <li>• <b>Demonstrate steps for putting on a condom (male and female) and offer to supply the client with condoms.</b></li> <li>• <b>Help client improve condom negotiation skills by:</b> <ul style="list-style-type: none"> <li>• <b>Responding to the clients questions and concerns</b></li> <li>• <b>Reassuring the client that it can be difficult to bring up the topic of condoms with a partner</b></li> <li>• <b>Suggesting that he or she discuss condoms BEFORE they are needed (not in the heat of the moment)</b></li> </ul> </li> </ul>
<b>5. Role play to encourage condom use</b>	
	<ul style="list-style-type: none"> <li>• <i>If partner asks: “But you have never suggested we use condoms before.”</i></li> <li>• <i>Client can say: “I went to the clinic today and my healthcare worker told me that I really need to use condoms for my health and so that we can prevent an unintended pregnancy.” (Or, the client may have another reason to explain a change of mind.)</i></li> <li>• <i>If partner asks: “You do not love me enough to have sex with out a condom?”</i></li> <li>• <i>Client can say, “It is because I love you and I love myself that I want to keep us both safe.”</i></li> <li>• <i>If partner says, “You want to use a condom because you have been messing around with other people.”</i></li> <li>• <i>Client can say, “Before we met, we both had other partners and I want to be sure that neither of us brings anything into the</i></li> </ul>

	<i>relationship.”</i>
<b>6. Encourage disclosure</b>	
	<ul style="list-style-type: none"> <li>• Encourage disclosure to partners, work with clients to facilitate the disclosure process, and offer the possibility of meeting with the client and partner together to help the client disclose (see Module 7).</li> </ul>



### **Trainer Instructions**

Slides 64-71

#### **Step 8:**

Ask participants:

- *Why do you think adolescent clients are vulnerable to STIs?*

Fill in using the content below.

#### **Step 9:**

Ask participants to brainstorm ways healthcare workers can make clinical examinations more adolescent-friendly and less stressful for adolescent clients. Present some steps that can be taken to do so, using the content below.

#### **Step 10:**

Ask participants what their experiences have been with STIs among their adolescent clients. Use these questions to guide the discussion:

- *What STI screening and treatment services are currently offered to adolescent clients? Are they offered as a routine part of clinical care? Are they provided at the HIV clinic or are clients referred to another clinic?*
- *What are the most common STIs among adolescents that you see?*
- *If STI services are not currently part of routine HIV care and treatment for ALHIV, why? Why is it important to integrate STI services into HIV care and treatment for ALHIV?*
- *What are some of barriers to integrating STI screening and treatment? What are some of the solutions?*

#### **Step 11:**

Remind participants that they should follow the national STI screening and treatment guidelines in their clinics. Review the guidelines as needed, as well as the key STI screening questions and examination steps for both female and male adolescent clients (which also appear in “Appendix 10C: Screening and Examining Adolescent Clients for STIs”).

#### **Step 12:**

(optional) Ask the adolescent co-trainer to give his or her inputs on how STI screening, counselling, and treatment can be integrated into care and treatment services, why these services are important to adolescents, and some of the ways he or she

thinks healthcare workers can make examinations less stressful for adolescent clients.



### **Make These Points**

- ALHIV are vulnerable to STIs for a number of reasons: biological factors (the genital tract of the adolescent is more susceptible to STIs), lack of knowledge, factors common in adolescence (risk taking, sexual violence, use of commercial sex workers or older partners, and fear of seeking treatment).
- SRH clinical procedures can be made more adolescent friendly through healthcare worker-client communication (for example, explain the process, give feedback in a non-judgemental manner), respect for privacy and confidentiality and same sex nurses or doctors.
- All adolescents who are sexually active should be screened for STI symptoms. If there is a suspicion of an STI, then conduct a physical examination. Follow the “National STI Syndromic Case Management Guidelines for Zambia” for diagnosis and treatment.
- Counsel a client with an STI on safer sex, partner referral, and treatment.

## **What Makes Adolescents Vulnerable to STIs?<sup>3</sup>**

Having an STI increases the risk of HIV transmission/acquisition. Many of the things that make adolescents vulnerable to HIV also make them vulnerable to STIs, such as the following.

### **Biological factors**

- The adolescent female genital tract, which is not yet fully mature, is more biologically susceptible to STIs than that of older women.
- ALHIV may have weakened immune systems, which make them more susceptible to STIs.
- Women often do not show signs or symptoms of chlamydia and gonorrhoea, the most common STIs, so infection may go untreated.

### **Lack of knowledge**

- Adolescents often lack basic knowledge about STI symptoms, transmission, and treatment.
- Adults are often uneasy talking with adolescents about STIs and sexual health, often thinking that they should not be having sex in the first place.

## **Factors common in adolescence**

- For adolescents, sex is often unplanned and spontaneous, making the use of condoms less consistent and increasing the risk for STIs. Adolescents may also have multiple, short-term sexual relationships.
- Young women are more at risk of sexual violence and exploitation, lack of formal education (including SRH education), inability to negotiate safer sex with partners, and lack of access to SRH information and services.
- Adolescents may be subject to high-risk behaviours, such as anal sex to preserve virginity, dry sex, and scarification, which can increase the risk for STIs.
- Young men may have their first sexual experiences with commercial sex workers and young women with older men, which can increase the risk of STIs if condoms are not used consistently and correctly.
- Adolescents may be afraid to seek treatment for STIs for fear of stigma and discrimination. This is especially true for ALHIV because many adults feel they should not be having sex at all.

## **Making SRH and Other Clinical Procedures More Adolescent-Friendly<sup>4</sup>**

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There are many ways healthcare workers can make physical examinations less stressful for adolescent clients. Be sure to:

- Explain what is going to happen during each visit.
- Respect the adolescent client's privacy, for example, leave the room and close the door if they need to remove clothing or change into a gown. Try and expose only the parts of the body you are examining, leaving the rest covered. Do not leave any part of the body exposed when not being examined.
- Explain what you are going to do before you begin each step of the examination.
- Reassure the client about confidentiality.
- Give the client reassurance throughout the examination.
- Give feedback in a non-judgemental manner. For example, "I see you have a small sore here, does it hurt?"
- Offer to have the exam performed by a doctor or nurse of the same sex, if possible. Or, offer to have someone of the same sex in the room during the examination.
- Delay pelvic exams, unless the adolescent client is at risk of STIs or pregnancy or has multiple sexual partners.
- If a pelvic exam is necessary, address any concerns. For example, adolescent girls who are virgins may fear that the procedure will be uncomfortable or tear their hymen. Healthcare workers can reassure clients that the hymen only partially covers the vaginal opening and that the vagina will stretch if the client can relax. Let the client see and touch the speculum, try to use a small speculum (sometimes called a "virgin speculum"), always explain what is going to happen, and ask permission to touch the client with your hand or the speculum. Take

great care to carry out all parts of the exam gently and smoothly to minimise the clients' discomfort and anxiety. Remind her to breathe deeply and try to relax during the exam.

## **STI Screening and Treatment for ALHIV**

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### **Screening and physical examination**

At every visit, ask adolescent clients who are sexually active (and **ALL** older adolescents clients — healthcare workers should assume they are sexually active or will be sexually active soon) about STI symptoms. If the answer to any question is 'yes', conduct a physical examination that includes the steps outlined in “Appendix 10C: Screening and Examining Adolescent Clients for STIs”. Ensure that there is privacy during all physical examinations and follow the tips to make examinations more adolescent-friendly (page 39).

Healthcare workers should also provide routine cervical screening on all sexually active women with HIV. Routine cervical screening is especially important as females living with HIV are at greater risk for cervical cancer than HIV-uninfected women.

See the “National STI Syndromic Case Management Guidelines for Zambia” for additional information.

### **Diagnosis and treatment**

A thorough physical examination is key to diagnosing STIs. Healthcare workers should use information from the physical examination in combination with the client's history to make a **syndromic diagnosis** and manage according to the flow charts in the national STI guidelines.

Treat clients diagnosed with an STI syndrome for all of the possible STIs that could cause that syndrome. In addition:

- Counsel clients to avoid sex while being treated for STIs and to use condoms with every sexual encounter after sexual activity resumes.
- Counsel clients diagnosed with STIs to inform their sexual partner(s) to seek medical care so that they can be evaluated and treated for STIs as well.
- Conduct risk reduction counselling to help adolescent clients avoid STIs in the future, including counselling on safer sex and consistent condom use with every sexual encounter.



#### **Trainer Instructions**

**Step 13:** Allow 5 minutes for questions and answers on this session.

## Session 10.5 Providing Childbearing and Contraceptive Counselling for ALHIV



**Total Session Time:** 115 minutes (1 hour, 55 minutes)



### Trainer Instructions

Slides 72-73

- Step 1:** Begin by reviewing the session objectives listed below.
- Step 2:** Ask participants if there are any questions before moving on.

### Session Objectives

**After completing this session, participants will be able to:**

- List the risks of adolescent pregnancy.
- Discuss childbearing choices and safe childbearing with adolescent clients.
- Understand adolescent-specific contraceptive issues and challenges.
- Counsel adolescent clients on prevention of mother-to-child transmission of HIV (PMTCT).

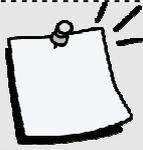


### Trainer Instructions

Slides 74-76

- Step 3:** Ask participants to brainstorm some of the risks of adolescent pregnancy, including health risks, and psychological, social, and economic consequences for both adolescent boys and girls. Record responses on flip chart and fill in using the content below.
- Step 4:** (optional) Ask the adolescent co-trainer to talk about some of the risks and consequences of adolescent pregnancy that he or she has seen among peers.
- Step 5:** Ask participants how they think healthcare workers can communicate the risks of adolescent pregnancy to their clients in a non-judgemental and supportive way that also respects their rights.
- Step 6:** Remind participants that many ALHIV have concerns about whether or not they can safely have children in the future. Review the key messages healthcare workers can give to their

clients (and their partners) about the ways and times people living with HIV can safely have children.



### **Make These Points**

- There are many health risks of early pregnancy for adolescents, including obstructed delivery, prolonged labour, pre-eclampsia, anaemia, premature birth, spontaneous abortion and stillbirth, as well as increased risk of haemorrhage, infection, and fistula.
- There are many psychological, social, and economic risks and consequences of adolescent pregnancy — for both girls and boys.
- Depending on the specific adolescent, her health status, adherence, and a number of other factors, there may also be an increased risk of MTCT.
- Given the risks of adolescent pregnancy, it is important that healthcare workers encourage their young clients to delay childbearing until they are adults, if possible, and to use contraceptive methods if they are sexually active. Healthcare workers can also provide counselling on the safest times to become pregnant, such as when the client has reached physical adulthood, when CD4 cell count is high, when the client is well, and when she is stable on and adhering to ART.

## **Risks of Adolescent Pregnancy<sup>5</sup>**

### **Health risks:**

- Pregnancy complications because they are not fully developed and their body may not be well prepared to handle child bearing. In these cases, there is a greater risk of obstructed delivery and prolonged labour, thereby increasing the risk of haemorrhage, infection, and fistula.
- Pre-eclampsia — or hypertension during pregnancy — which, if left untreated can progress to extreme hypertension, seizures, convulsions, and haemorrhage.
- Anaemia, which is more common in adolescent mothers than in older mothers.
- Complications associated with unsafe abortion.
- Premature births and low birth weight.
- Spontaneous abortion and stillbirths, especially among adolescents under the age of 15.
- Mother-to-child transmission if an ALHIV becomes pregnant. ART and ARVs can help reduce, but not eliminate, the risk (see below for more information on PMTCT).

## **Psychological, social, and economic risks and consequences:**

- Pregnant adolescents, and especially those living with HIV, may face intense stigma from family, friends, community members, and healthcare workers — which can cause emotional distress and create an impediment to receiving needed HIV and PMTCT care and medicines.
- Pregnancy often means the end of formal education. If not expelled from school if pregnant, girls often have to drop out to care for the infant.
- Adolescent pregnancy can change a girl's choice of career, academic aspirations and future marriage possibilities. With limited career prospects, some mothers resort to low paying and risky jobs (such as prostitution) or marriage to support their children.
- Some men refuse to take responsibility for the pregnancy which can contribute to hardship for the mother and child.
- Young parents are often not prepared to raise a child, which could in extreme cases lead to child rearing problems like child abuse or neglect.
- Early marriage due to an unplanned pregnancy is frequently an unhappy, unstable one.

## **Counselling Adolescents on the Safest Times to Have Children in the Future**

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Many ALHIV have questions about whether or not they can safely have children in the future. Healthcare workers should provide education and counselling to adolescent clients on the safest times to become pregnant and have children.

- It is safest to wait until adulthood to become pregnant and have children. There are many health, psychological, social, and economic risks of having a baby during adolescence (see above).
- The safest time to get pregnant is when **both** partners:
  - Have CD4 cell counts over 350
  - Are healthy: they do not have any opportunistic infections (including TB) nor do they have advanced AIDS
  - Are taking and adhering to their ART regimens
- It is healthiest for a mother to wait until her child is at least 2 years before getting pregnant again.

It is important for ALHIV to know the facts about pregnancy and preventing mother-to-child transmission — BEFORE they become pregnant. These are good topics to discuss in ALHIV support groups and during individual counselling sessions. Adolescent clients should always be encouraged to talk with healthcare workers about pregnancy and PMTCT if they are thinking of having children. Healthcare workers should also encourage partners of adolescent clients to come to the clinic for education and counselling on these topics.



## Trainer Instructions

Slides 77-82

- Step 7:** Ask participants to reflect on what contraceptive counselling and contraceptive methods are currently available to adolescent clients within the HIV care and treatment clinic. Remind participants of the importance of “one-stop shopping” for adolescent clients. This includes the provision of contraceptive counselling and at least some forms of contraception (for example, condoms, pills, injectables) within the HIV care and treatment clinic.
- Step 8:** Review the common contraceptive issues among adolescents as well as common side effects. Remind participants to always follow national family planning guidelines.
- Provide an overview of contraceptive options available to ALHIV. Start the discussion by asking:
- *What contraceptives are available to ALHIV?*
- Record the options on flip chart paper. Give hints until participants have listed the 10 options in Table 10.3. Then for each option ask:
- *What are the main advantages of this option?*
  - *Disadvantages?*
  - *Given the advantages and disadvantages, what do you think about this option for ALHIV?*
- Where there are questions, refer to “Appendix 10D: Survey of Family Planning Methods for Adolescents”. Refer participants to the same appendix to review special considerations for the adolescent client and key points for counselling the adolescent client.
- Reiterate that most methods are safe and effective for ALHIV, as long as proper counselling and follow up are provided.
- Step 9:** (optional) Ask the adolescent co-trainer to comment on the needs for contraceptive counselling and methods he or she sees among his or her peers and how healthcare workers and HIV care and treatment programmes can help address these needs.



### **Make These Points**

- It is important to consider an adolescent's lifestyle, personality, and social situation before recommending and prescribing a family planning method. For example, an adolescent may be more adherent to her family planning decision, if the method does not require a daily regimen or if it allows her to conceal sexual activity and contraceptive use.
- Good education and counselling — both before and at the time a method is selected — can help adolescents make informed, voluntary decisions with which they are more likely to adhere in the long term. Counselling should always include discussion of side effects.
- The following family planning methods are good options for ALHIV: condoms, COCs/POPs, injectables, hormonal implants and IUDs. Some of these options include caveats, for examples the hormonal methods may be less effective in clients on ART, so clients must be advised to use condoms in addition to the hormonal method.
- Ensure that all ALHIV clients know about emergency contraceptive pills, when they can be used and how to obtain them.
- Counsel all clients on correct condom use, whether condoms are their primary contraceptive choice or will be used for dual protection.

## **Common Contraceptive Issues for Adolescents**

- Adolescents have special needs when choosing a contraceptive method. Social and behavioural issues are important considerations. For example, methods that do not require a daily regimen may be more appropriate because of adolescents' unpredictable sexual activity or the need to conceal intimacy and contraceptive use. In addition, sexually active adolescents who are unmarried have very different needs from those who are married and want to postpone, space, or limit pregnancy.
- However, whether married or unmarried, adolescents have been shown to be less tolerant of side effects and to have high family planning discontinuation rates. Expanding the number of methods to choose from can improve adolescents' satisfaction and increase contraceptive acceptance and use. Proper education and counselling — both before and at the time a method is selected — can help adolescents make informed, voluntary decisions.
- At a minimum, all adolescents should be counselled on correct condom use and clearly instructed that condoms or abstinence are the only ways to prevent HIV infection. Every effort should be made to prevent the cost of services or contraceptive methods from limiting options.

Always follow the national “Family Planning Counselling Kit” when providing family planning counselling and support and when prescribing a family planning method.

### Contraceptive Side Effects:

Some adolescents may experience side effects from contraceptive methods (i.e. weight gain, spotting, menstrual changes). These side effects can be uncomfortable, annoying, or worrisome to clients. Side effects are the major reason that adolescent clients stop using contraceptive methods. Therefore it is important that healthcare workers<sup>6</sup>:

- Treat all client complaints with patience and seriousness.
- Offer clients an opportunity to discuss their concerns.
- Reassure the client that side effects are manageable and reversible.
- Help the client differentiate between normal contraceptive side effects versus complications that require a return visit to the clinic.
- Offer clients information and advice on how to prevent/manage side effects.
- Always provide follow-up counselling.

A summary of common contraceptive options for ALHIV is in Table 10.3. A more detailed description of contraceptive options including special considerations for the adolescent client and advice on counselling the adolescent client about condoms can be found in “Appendix 10D: Survey of Family Planning Methods for Adolescents”.

**Table 10.3: Summary of contraceptive options for ALHIV**

Male and female condoms		
Advantages	Disadvantages	Summary
<ul style="list-style-type: none"> <li>• Provide protection from both pregnancy and STI (including HIV) transmission and acquisition</li> <li>• Highly effective when used consistently and correctly</li> </ul>	<ul style="list-style-type: none"> <li>• Correct and consistent condom use may be difficult to achieve, failure rates can be high.</li> <li>• Partner involvement is required, need to negotiate their use</li> <li>• Does not interfere with medications</li> </ul>	<ul style="list-style-type: none"> <li>• Good method for adolescents</li> <li>• Requires demonstration on proper use</li> </ul>
Combined oral contraceptive pills (COCs), progestin-only oral contraceptive pills (POPs) — pills taken daily*		
Advantages	Disadvantages	Summary
<ul style="list-style-type: none"> <li>• Highly effective when taken daily on schedule</li> <li>• POPs may be a good choice for adolescents who cannot tolerate estrogen in COCs or who are breastfeeding</li> <li>• Does not interfere with sex</li> </ul>	<ul style="list-style-type: none"> <li>• Failure rates highest for adolescents due to confusion about how to take pill</li> <li>• Side effects can include nausea, weight gain, breast tenderness, headaches, spotting</li> <li>• Cannot be taken by clients on rifampicin</li> <li>• ARVs may adversely</li> </ul>	<ul style="list-style-type: none"> <li>• Women taking ARVs who want to use COCs should be counselled about the importance of taking COCs on time every day, and about consistent condom use</li> <li>• POPs are safe for adolescents, but because they must be taken at exactly the</li> </ul>

	affect the efficacy of low-dose COCs and/or increase their side effects	same time everyday, they are not the best choice
<b>Injectables — “shot” given every 2–3 months*</b>		
<b>Advantages</b>	<b>Disadvantages</b>	<b>Summary</b>
<ul style="list-style-type: none"> <li>Highly effective when used correctly</li> <li>Does not interfere with sex</li> </ul>	<ul style="list-style-type: none"> <li>Side effects can include spotting at first, then amenorrhea and weight gain</li> </ul>	<ul style="list-style-type: none"> <li>Can be used by ALHIV without restrictions</li> <li>Remind adolescent when to return for next injection</li> </ul>
<b>Hormonal implants — small rods inserted under skin, lasts 3–7 years*</b>		
<b>Advantages</b>	<b>Disadvantages</b>	<b>Summary</b>
<ul style="list-style-type: none"> <li>Highly effective</li> <li>Can be reversed</li> <li>Does not interfere with sex</li> </ul>	<ul style="list-style-type: none"> <li>Effectiveness of implant may be reduced by ARVs</li> <li>Side effects can include nausea, weight gain, and changes in monthly bleeding.</li> <li>Usually need to be inserted and removed at a family planning clinic</li> </ul>	<ul style="list-style-type: none"> <li>Can be used by ALHIV who do not take ART</li> <li>Can be used by ALHIV on ART, but should use condoms as a back-up method</li> <li>Provide counselling to prepare client for possibility of irregular bleeding</li> </ul>
<b>Emergency contraceptive pills (ECP) — 2 doses of pills taken within 120 hours after unprotected sex</b>		
<b>Advantages</b>	<b>Disadvantages</b>	<b>Summary</b>
<ul style="list-style-type: none"> <li>Reduces risk of pregnancy after unprotected sex by 75%</li> <li>Safe for all women, including those living with HIV and those taking ART</li> </ul>	<ul style="list-style-type: none"> <li>For emergency use only!</li> <li>Side effects can include nausea, vomiting, cramps, headache, breast tenderness, and changes in the menstrual cycle</li> </ul>	<ul style="list-style-type: none"> <li>Should be widely and easily available to ALHIV</li> <li>Provide counselling on adopting a regular contraceptive method, as well as on condom use for dual protection</li> </ul>
<b>Intra-uterine devices (IUDs) — device inserted into uterus, lasts up to 12 years*</b>		
<b>Advantages</b>	<b>Disadvantages</b>	<b>Summary</b>
<ul style="list-style-type: none"> <li>Highly effective</li> <li>Does not interfere with sex</li> </ul>	<ul style="list-style-type: none"> <li>Should not be initiated in a woman with AIDS not taking ART</li> <li>Side effects can include heavy bleeding, discharge, cramping and pain during the first months</li> <li>Usually needs to be inserted and removed at a family planning clinic</li> </ul>	<ul style="list-style-type: none"> <li>Appropriate for adolescents in stable, mutually monogamous relationships</li> <li>Not recommended for ALHIV with advanced HIV disease or AIDS, especially if not on ART</li> </ul>
<b>Male and female sterilisation — surgery*</b>		
<b>Advantages</b>	<b>Disadvantages</b>	<b>Summary</b>
<ul style="list-style-type: none"> <li>Safe and effective</li> <li>Free of side effects</li> <li>Does not interfere with sex</li> </ul>	<ul style="list-style-type: none"> <li>Permanent and requires surgery</li> </ul>	<ul style="list-style-type: none"> <li>Permanent methods are not recommended for adolescents</li> </ul>
<b>Lactational amenorrhea method (LAM)*</b>		
<b>Advantages</b>	<b>Disadvantages</b>	<b>Summary</b>

<ul style="list-style-type: none"> <li>• Temporary, natural contraceptive option for women who are less than 6 months postpartum, exclusively breastfeeding, and whose periods have not yet returned</li> </ul>	<ul style="list-style-type: none"> <li>• Most adolescents will not be breastfeeding (unless they have infants), so this is not a likely option for ALHIV</li> </ul>	<ul style="list-style-type: none"> <li>• Appropriate only for adolescents who have given birth within the past 6 months</li> </ul>
Fertility awareness methods*		
Advantages	Disadvantages	Summary
<ul style="list-style-type: none"> <li>• No health risks or side effects</li> </ul>	<ul style="list-style-type: none"> <li>• Requires a woman to identify her fertile days, which takes time and effort</li> <li>• Requires considerable commitment, calculation and self-control, both by the woman and her partner</li> </ul>	<ul style="list-style-type: none"> <li>• A difficult method for most adolescents to implement correctly and consistently</li> <li>• Not reliable for pregnancy prevention</li> <li>• Do not recommend</li> </ul>
* Healthcare workers should recommend and provide condoms for dual protection.		

Adapted from: Senderowitz, J., Solter, C., & Hainsworth, G. 2002, revised 2004. *Comprehensive Reproductive Health and Family Planning Training Curriculum: Module 16: Reproductive Health Services for Adolescents, Unit 7.* Watertown, MA: Pathfinder International.



### Trainer Instructions

Slides 83-85

**Step 10:** Ask, by a show of hands, how many participants have received training in PMTCT. Encourage any participants that have not received training in PMTCT to do so, as this is also an important component of adolescent HIV care and treatment services.

Remind participants that they should always follow the Zambia “2010 National Protocol Guidelines — PMTCT” when providing PMTCT services to adolescent clients. Remind participants that the PMTCT guidelines were updated in 2010.

Review the key concepts of PMTCT during pregnancy, labour and delivery, postpartum, and during infant feeding.

**Step 11:** Ask participants to brainstorm some common concerns or issues adolescents might face with PMTCT and lead a discussion on the special issues ALHIV face with pregnancy and PMTCT.

**Step 12:** (optional) Ask the adolescent co-trainer to give insights into the concerns and needs of ALHIV who become pregnant and what healthcare workers can do to help support them to stay healthy and prevent MTCT.



### Make These Points

- Key concepts in the Zambia PMTCT protocol guidelines include the following:
  - Keep mothers healthy — the higher her CD4 cell count the less likely her infant will be HIV infected
  - Reduce risk at every stage — pregnancy, labour, delivery and during breastfeeding
  - All mothers need ARVs — mothers with CD4 cell count below 350 are eligible for lifelong ART, those with CD4 cell count above 350 should get ARVs during pregnancy
  - All babies of HIV-infected mothers need ARVs and CTX — for the first six weeks of life; if mother is breastfeeding, either mother or baby will take ARVs during the entire breastfeeding period

## PMTCT Services for Adolescents

Healthcare workers should follow the Zambia “2010 National Protocol Guidelines — PMTCT” when providing services to pregnant ALHIV, their partners, and family members. Some of the key PMTCT concepts are summarised below.

**Table 10.4: Key PMTCT concepts**

### Key Concept 1 – Keep mothers healthy

- The healthier the mother (the less HIV she has in her blood and the higher her CD4 cell count), the less likely it is that the baby will become HIV-infected. Conversely, the sicker the mother (a lot of virus in the blood and low CD4 cell count), the more likely it is that the baby will become HIV-infected.
- A healthy mother is able to take care of herself, her baby and her family. Without healthy mothers, we will not have healthy families or communities!

### Key Concept 2 – Reduce risk at every stage

The risk of passing HIV from a mother living with HIV to her baby depend on timing:

- During pregnancy, labour and delivery, about 20 out of 100 babies will get HIV if there are no ARVs or other services offered.
- During breastfeeding, about 12 out of every 100 babies in the absence of a PMTCT programme. This depends on how the baby is fed — mixed feeding in the first 6 months of life dramatically increases risk — and how long the baby is breastfed.

**It is important to reduce the risk of transmission at each of these stages.**

### Key Concept 3 – All mothers need ARVs

- One of the best ways to lower the amount of HIV in the mother’s body, increase her CD4 cell count and make her healthy and less likely to pass HIV to the baby is for her to get the care and treatment she needs to be as healthy as possible, including ART. All pregnant women with HIV need to take ARVs.
- If a mother has a CD4 cell count **at or below 350**, the baby is at high risk of getting HIV. According to the national PMTCT guidelines, women with a CD4 cell count of 350 or lower should start ART and stay on ART for their entire lives.
- If a mother has a CD4 cell count **above 350**, the baby has a lower risk of getting HIV than if the mother’s CD4 cell count is low. According to new national recommendations, women with a CD4 cell count above 350 should also get ARVs during pregnancy to prevent the baby from acquiring HIV. Follow the Zambia “2010 National Protocol Guidelines — PMTCT”.

### Key Concept 4 – All babies of HIV-infected mothers need ARVs and CTX

- All babies need to take daily NVP at the time of birth and for the first six weeks of life, to help prevent them from becoming HIV-infected. If baby is breastfed and mother is not on ART, then the baby will continue taking daily NVP until one week after complete cessation of all breastfeeding. Babies of mothers on ART and those who are formula feeding, stop taking NVP at 6 weeks of age.
- Either the mother or the baby needs to be taking ARVs for the **entire time the baby is breastfeeding**. This helps protect the baby from getting HIV during breastfeeding.
- HIV-exposed babies need to take CTX starting at 6 weeks to prevent other infections that may make them very sick or lead to a rapid death. Babies should take CTX until it is certain that they are not HIV-infected.
- If the baby gets tested and is HIV-infected, the baby will also need lifelong ART (The Zambia MoH recommends that all HIV-infected babies under age 2 years begin ART).

## Challenges with PMTCT Services

Pregnant adolescents and new adolescent mothers, and their partners, face many of the same challenges adults face with PMTCT. However, healthcare workers should keep in mind challenges that could present barriers to adolescent clients in PMTCT programmes, including:

- Difficulty and challenges adhering to ART or ARVs
- Difficulty and challenges giving the baby medicines everyday
- Challenges with safe infant feeding, especially exclusive breastfeeding for the first 6 months of life
- Fears about having a baby that is HIV-infected; guilt about passing HIV to the baby

- Facing stigma for having HIV and becoming pregnant, and for being pregnant at a young age, especially if not married
- Difficulty foreseeing the future and lifelong HIV care, while also caring for a child
- Lack of emotional and financial support from family and/or from the child's father
- Financial instability and possibility of dropping out of school
- Inadvertent disclosure of HIV status to others
- Lack of access to youth-friendly PMTCT information and PMTCT services



### Trainer Instructions

Slides 86-86

**Step 13:** Lead participants through Exercise 5, which gives an opportunity to discuss and practise providing a range of sexual and reproductive health information, counselling, and services to adolescent clients.

<b>Exercise 5: Providing SRH Services to Adolescent Clients: Case studies, role play, and large group discussion</b>	
<b>Purpose</b>	<ul style="list-style-type: none"> <li>• Participants have an opportunity to discuss and role play strategies to provide ALHIV with a range of sexual and reproductive health information, counselling, and services</li> </ul>
<b>Duration</b>	60 minutes
<b>Advance Preparation</b>	<ul style="list-style-type: none"> <li>• Review the case studies ahead of time and make any adjustments, as needed, so that they reflect the local context.</li> </ul>
<b>Introduction</b>	Explain that we have covered a lot of information on providing ALHIV with sexual and reproductive health information, counselling, and services in this module. Now, participants will review and role play case studies to practise and apply some of the skills they have learned.
<b>Activities</b>	<p><b>Case Studies and Role Play</b></p> <ol style="list-style-type: none"> <li>1. Break participants into small groups of 3–4 people each.</li> <li>2. Assign each small group 2 of the case studies listed below, and in the Participant Manuals. Ask participants to review their case studies, recording key points on flip chart.</li> <li>3. Ask each small group to role play their 2 case studies, taking turns playing the roles of “healthcare worker,” “adolescent client,” and “observer.” In some cases, there may be an additional role of the client’s family member.</li> </ol> <p><b>Large Group Discussion</b></p>

	<p>4. Bring the large group back together and invite some of the small groups to perform 1 of their role plays. Lead a discussion in the large group, using these questions as a guide:</p> <ul style="list-style-type: none"> <li>• <i>What were the main SRH issues for this client? What do you think the client was thinking and feeling when he or she was with the healthcare worker?</i></li> <li>• <i>How did the healthcare worker address the client's needs? What kinds of assessments and screening did he or she conduct?</i></li> <li>• <i>What kind of education and counselling did the healthcare worker offer the client? What was good about this and what do you think could have been done better or differently?</i></li> <li>• <i>What age-appropriate communication techniques/approaches did the healthcare worker use to build trust and make the client feel comfortable? What was done well and what do you think could have been done better or differently?</i></li> </ul> <p>5. (optional) Encourage participation from the adolescent co-trainer, who can act as the adolescent client in some of the role plays. Ask the following questions to encourage discussion:</p> <ul style="list-style-type: none"> <li>• <i>How do you think the adolescent client was feeling in this situation? What might have been some of his or her concerns or fears?</i></li> <li>• <i>What did the healthcare worker do well to communicate with the client? What could have been done better or differently?</i></li> <li>• <i>How did the healthcare worker address the client's specific SRH concerns and needs? What was done well and what could have been done better or differently?</i></li> </ul>
<b>Debriefing</b>	<ul style="list-style-type: none"> <li>• Healthcare workers play important roles in providing ALHIV with accurate advice, information, counselling, and clinical services related to their sexual and reproductive health.</li> <li>• Sometimes adults — including healthcare workers, feel uncomfortable talking about sexual and reproductive health with young people, but it is an important part of comprehensive care, positive living, and preventing new HIV infections.</li> <li>• Sexual and reproductive issues are sensitive and sometimes embarrassing issues for adolescents. Therefore, it is always important to try and make adolescents feel comfortable and to “normalise” SRH services as a standard part of comprehensive HIV care and treatment. Healthcare workers should try to use</li> </ul>

	good communication techniques, ensure a youth-friendly environment, and project an open, and non-judgemental attitude about clients' behaviours and choices.
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### **Exercise 5: Providing SRH Services to Adolescent Clients: Case studies, role play, and large group discussion**

#### **Case Study 1:**

The mother of one of your adolescent clients, named Isaac, comes to the clinic to speak with you. She is very upset because she caught Isaac, who is 15, looking at pornographic magazines. She went through Isaac's things and was shocked to see photos of men having sex with other men. She tells you that she does not want Isaac coming to the adolescent support group anymore, because she thinks it is a bad influence and that the "city kids" might be "making him gay." What would you talk about with Isaac's mother? How would you proceed when you see Isaac during his clinical check up?

#### **Key points for trainers: Isaac**

- You, as the healthcare worker, should meet with Isaac's mother on a one-to-one basis. When you talk with her, use your listening and learning skills (Module 4) (particularly "Skill 5: Empathise — Show that you understand how the client feels") and listen to Isaac's mother, acknowledge that she is upset, encourage her to discuss how she feels.
- Re-frame the role of the support group for her. Acknowledge that the support group is encouraged to show tolerance to all of its participants, regardless of sexual orientation. The support group also encourages participants to abstain for sex, but those adolescents who choose not to abstain, are reminded of their responsibility to use condoms and supported to negotiate safer sex. So, most adolescents in the support group are less likely to take risks than those who do not participate in the group.
- Remember that curiosity about various ways of sexual expression is normal at this age. It is possible that this particular curiosity is a passing phase.
- When you meet with Isaac on a one-to-one basis, tell him that you have just spoken to his mother and that she is quite upset. Summarise what you have agreed with his mother. Ask him what he thinks about the situation. Advise based on his response. If Isaac is gay (it is more likely that looking at male pornography is driven by curiosity rather than sexual orientation, but you will not know till you ask), encourage him to embrace his sexuality. He will also need much support as a gay man to live in a world that can be very prejudice against sexual minorities. Provide referrals if appropriate.
- Set a date and time to meet again.

**Case Study 2:**

A noisy group of young boys are in the waiting room of the clinic laughing and talking loudly. They push one of the boys towards you and say: “He needs some condoms.” The boy, named Themba, is about 16 years old, looks embarrassed and does not say anything. Themba comes in for his check up. How would you proceed with Themba? How would you make him feel comfortable since he’s already embarrassed, what questions would you ask him, and what information and services would you provide?

**Key points for trainers: Themba**

- There are any number of ways to handle this. Maybe the most direct way is to (once you are and Themba are alone) hand him a bunch of condoms and then proceed with the sexual risk screening (see “Table 10.1: Sexual risk screening” on page 35) followed by risk reduction counselling (see “Table 10.2: Risk reduction counselling” on page 35) including a discussion of disclosure.
- Be sure to let Themba know that although it can feel embarrassing to ask for condoms, it’s OK and that you really appreciated the opening to discuss safer sex with him today. Praise him for wanting to use condoms — an important step in positive prevention!

**Case Study 3:**

Susan is a 15-year-old girl who has been brought to the clinic by her aunt. Her aunt tells you that she thinks Susan has an older boyfriend and that he is buying her new clothes and perfumes. Susan seems shy and unwilling to speak in front of her aunt at the clinic visit. How would you proceed with Susan? What kind of questions would you ask her and what kinds of information and counselling would you provide?

**Key points for trainers: Susan**

- First, as convenient and appropriate, meet with Susan on a one-to-one basis. Discuss a few general topics first (see “Appendix 5A: Psychosocial Assessment Tool” in Module 5).
- Ensure that the discussion leads into the sexual risk screening (see “Table 10.1: Sexual risk screening” on page 35) followed by risk reduction counselling (see “Table 10.2: Risk reduction counselling” on page 35).
- Find out if there are issues at home. Although not unusual for a 15 year old to seek out an older boyfriend, it may mean that she is running away from issues at home.
- You may also want to assess her well-being (see “Table 6.5: Assessment of Well Being Screening Tool” in Module 6) and screen for further mental health issues (such as depression).

**Case Study 4:**

Peter is a 19-year-old young man who comes to the ART clinic regularly. You learned from one of the adolescent Peer Educators at your clinic that Peter was bragging that he has been with "about 10 women" but never uses condoms because they are "good girls" and they do not insist that he uses condoms, so why should he? When you offer him some condoms at the end of the appointment, he says that he does not need them. He says that he now has a steady girlfriend because he is feeling pressure from family to "get serious". How do you proceed with Peter?

**Key points for trainers: Peter**

- Ask Peter which family planning method he and his steady girlfriend use. If she is not using any contraceptives, recommend using condoms for now, until he and his girlfriend can either come to the ART clinic for family planning counselling or go to a family planning clinic. Regardless of her family planning choice, he should still continue to use condoms to protect her from HIV.
- Ask if she knows his HIV status. If she does not, ask him when he plans to tell her. Discuss and provide counselling and support around disclosure (see Module 7). Discuss his responsibility to ensure that she is protected from HIV. If he responds with an attitude suggesting that he does not care, remind him that the law protects her right to remain free from HIV and if he is found to have purposely infected her with HIV, then he can be imprisoned.
- Ask if he has any former partners that need to know their risk of HIV infection. Ask him to suggest a plan for informing them of their risk.
- Ensure he is adhering to his ART regimen (if eligible).
- Give him condoms and arrange date and time for a follow-up visit.

**Case Study 5:**

George is a 16-year-old client who has been coming to the ART clinic since his childhood. You ask George if he is having any problems, and shyly, he tells you that he is having a lot of pain when he pees. You begin asking him some more questions about his symptoms and whether or not he is sexually active (he just nods his head "no" – that he is not sexually active) and he seems embarrassed, stops talking, and just looks down at the floor. How do you proceed with George?

**Key points for trainers: George**

- When you counsel George use your listening and learning skills (Module 4) (particularly "Skill 5: Empathise — Show that you understand how the client feels"). "*George you seem embarrassed about something, is there something you would like to discuss?*" Give him time to muster the courage to talk to you. If he continues to

refuse to talk, then start with general questions (see “Appendix 5A: Psychosocial Assessment Tool” in Module 5).

- When you get to the questions about sexual risk, casually mention that difficulty peeing may be due to an STI such as nongonococcal urethritis (NGU). Faced with facts, he is likely to start to open up.
- Even if he does not open up lead the discussion into a sexual risk screening (see “Table 10.1: Sexual risk screening” on page 35) followed by risk reduction counselling (see “Table 10.2: Risk reduction counselling” on page 35).
- Stress that the presence of an STI makes it clear that he has had unsafe sex. Let him know that having sex is OK, so long as you take responsibility for your HIV status. Emphasize the importance of condom use and continued adherence to his ART regimen.
- Depending on how the conversation goes, you may also want to assess his well-being (see “Table 6.6: Assessment of Well Being Screening Tool” in Module 6) and screen for further mental health issues (such as depression).

### **Case Study 6:**

Ethel is a 16 year-old young woman who tested positive for HIV and recently started coming to the clinic. Ethel thinks she is sure that she contracted HIV from her ex-boyfriend. When Ethel tells you she is having some strange vaginal discharge, you suggest that you do a clinical exam because she might have an STI. Ethel starts crying and says she refuses to have anyone touch her “down there.” How would you proceed with Ethel?

#### **Key points for trainers: Ethel**

- When you counsel Ethel use your listening and learning skills (Module 4) (particularly “Skill 5: Empathise — Show that you understand how the client feels”). “*Ethel, you seem upset about the possibility that I may have to conduct an internal exam, can you tell me why? Are you in a lot of pain?*” See how she responds.
- If she truly does not want to do the clinical exam, then offer to postpone the exam. If possible, prescribe presumptively based on symptoms. Then take the session to a counselling room (if possible away from the examination room). Start with some general questions and then conduct the psychosocial assessment (see “Appendix 5A: Psychosocial Assessment Tool” in Module 5).
- When you get to the questions about rejection and isolation, pay special attention to her response to the question: “*Has anyone caused you harm in the past; for example, hurt you physically or unwanted sexual encounters?*”
- Depending on how the conversation goes, you will probably also want to assess well-being (see “Table 6.7: Assessment of Well Being Screening Tool” in Module 6) and screen for further mental health issues (such as depression).

- If she has experienced sexual violence, provide support and referrals. Provide any other needed referrals, make an appointment for a follow-up visit.

### **Case Study 7:**

Katherine is a 17-year-old young woman living with HIV. She is on ART and is feeling very well. She has a boyfriend and he knows about her HIV status and is accepting. She was taking oral contraceptives but stopped them because she said they made her feel nauseous and gain weight. Now, they usually use condoms, but they have had sex a few times without them. Katherine and her boyfriend do not want children right now, but they talk about getting married and having children in the future, once she finishes school. Katherine is getting a lot of pressure from her family to never have kids because of the risk that they would be HIV-infected. How would you proceed with Katherine?

#### **Key points for trainers: Katherine**

- It seems as if oral contraceptives are not working for Katherine. Reassure her that it is fine, many women cannot take oral contraceptives. Find out more about her preferred form of contraception: how did she do taking contraceptive pills daily? Did she ever miss a dose? If no, might she prefer to try POPs (rather than the COCs)? Would she prefer a form of birth control such as injectables, hormonal implants or the IUCD, which doesn't need to be taken daily? Provide her with additional information and counselling around her preferred options.
- Make sure she continues to use condoms as a back up method. Ask her why she and her boyfriend stopped using them for a while. Provide responses to her or her boyfriend's condom-related questions or issues. Offer to meet with her and her boyfriend to discuss contraception, HIV risk, HIV testing and to respond to any questions that her boyfriend may have.
- Provide her with information about emergency contraception: what it is, how to get it, when to get it.
- Offer to meet with her family to discuss future childbearing with a focus on low rates of MTCT for women who take advantage of PMTCT interventions.

### **Case Study 8:**

Elizabeth is 19 years-old and was perinatally infected with HIV. She has been adherent to ARVs for many years. She has come to the clinic today for a check up because she is pregnant. She is happy to be pregnant, but is afraid that her baby will become HIV-infected. She is also worried about how her ARVs might be affecting her unborn child, and tells you that her boyfriend has told her to stop taking them so they do not hurt the baby. How would you proceed with Elizabeth?

### Key points for trainers: Elizabeth

- Congratulate Elizabeth on her pregnancy.
- Tell her about the PMTCT services available through ANC. Let her know that you will work with staff at the ANC clinic to ensure that she gets the best care possible. Part of that care will be ensuring she stays on ART. Let her know that her ART regimen presents little risk to the unborn infant. Actually it is very positive that she is already on ART. Revisit the importance of adherence. Explain to her that if her adherence is excellent and continues throughout her pregnancy and breastfeeding, she is unlikely to transmit HIV to her baby.
- Offer to meet together with her boyfriend to discuss PMTCT services further. For the moment, urge her not to stop taking her ARVs.
- Provide a referral to ANC. Set a date to meet with Elizabeth and her boyfriend.



#### Trainer Instructions

**Step 14:** Allow 5 minutes for questions and answers on this session.



#### Trainer Instructions

Slides 97-101

**Step 15:** Ask participants what they think the key points of the module are. What information will they take away from this module?

**Step 16:** Summarise the key points of the module using participant feedback and the content below.

**Step 17:** Ask if there are any questions or clarifications.



### Module 10: Key Points

- An important part of adolescent HIV care and treatment is assessing and responding to the SRH needs of clients. In order to do so, healthcare workers must be comfortable talking about sexuality and SRH with their clients and knowledgeable about the common SRH issues faced by adolescents.
- Healthcare workers need to stress that homosexual, bisexual, and

transsexual/transgendered behaviour is NORMAL (regardless of the healthcare worker's personal views). Healthcare workers do not have to be experts on sexual orientation. A willingness to listen, be understanding, and refer adolescent clients to resources is often enough.

- Safer sex describes the range of sexual activities that do not transmit STIs (including HIV) and that protect against unintended pregnancy but are still pleasurable. Safer sex includes sexual practices during which body fluids are not passed between partners. Using condoms is a reliable way to practise safer sex and prevent STIs, HIV and unwanted pregnancy. For people who are living with HIV, condoms also prevent re-infection. ALHIV should have free and easy access to condoms in the clinic setting.
- Sexual risk screening starts before a client is sexually active and includes questions to help the healthcare worker assess if the client is sexually active, if so, with whom and what risks he or she is taking. Risk reduction counselling focuses on reducing risk of HIV, STIs and unwanted pregnancy by helping the client choose a strategy that is right for him or her.
- All adolescents who are sexually active should be screened for STI symptoms. If there is a suspicion of an STI, then conduct a physical examination. Follow the national STI guidelines for diagnosis and treatment.
- Given the risks of adolescent pregnancy, it is important that healthcare workers encourage their young clients to delay childbearing until they are adults, if possible, and to use contraceptive methods if they are sexually active. Healthcare workers can also provide counselling on the safest times to become pregnant, such as when the client has reached physical adulthood, when CD4 cell count is high, when the client is well, and when she is stable on and adhering to ART.
- Good education and counselling — both before and at the time a method is selected — can help adolescents make informed, voluntary decisions with which they are more likely to adhere in the long term. Counselling should always include discussion of side effects.
- The following family planning methods are good options for ALHIV: condoms, COCs/POPs, injectables, hormonal implants and IUDs.
- Counsel all clients on correct condom use, whether condoms are their primary contraceptive choice or will be used for dual protection.
- Ensure that all ALHIV clients know about emergency contraceptive pills, when they can be used and how to obtain them.
- Refer all pregnant clients to ANC for PMTCT services.

## Appendix 10A: Journal Article

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Journal of Adolescent Health 44 (2009) 184–187

Adolescent health brief

### Sexual Behavior and Desires Among Adolescents Perinatally Infected with Human Immunodeficiency Virus in Uganda: Implications for Programming

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See Editorial p. 101

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**Abstract** Counseling programs for adolescents living with human immunodeficiency virus (HIV) encourage abstinence from sex and relationships. This Uganda study, however, found that many of these adolescents are sexually active or desire to be in relationships but engage in poor preventive practices. Programs for HIV and acquired immunodeficiency syndrome (AIDS) programs therefore need to strengthen preventive services to this group. © 2009 Society for Adolescent Medicine. All rights reserved.

**Keywords:** Adolescents; HIV infection; Perinatal; Sexual behavior; Program implications; Uganda

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The number of children living with human immunodeficiency virus (HIV) in Africa continues to escalate despite the advances made in prevention of mother-to-child transmission. Sub-Saharan Africa accounts for 90% of the estimated 3 million children living with HIV [1]. At the same time, the roll-out of anti-retroviral treatment (ART) programs has made it possible for perinatally HIV-infected infants to live through adolescence and adulthood thereby engaging in dating and sexual relationships. However the sexual and reproductive health needs of this unique and growing group of the population are largely unmet [2]. In Uganda, for example, treatment, care, and support programs for HIV and acquired immunodeficiency syndrome (AIDS) are organised around adult and pediatric care. This implies that adolescents who no longer fit under pediatric care and who feel uncomfortable with adult services lack programs to address their specific

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needs. Moreover the programs assume that HIV-infected young people remain sexually inactive and therefore hardly address their need for sexual and reproductive health information and services. Service providers and counselors, for instance, usually advise perinatally infected adolescents not to engage in sexual relationships [3,4]. In its efforts and continued commitment to care for people living with HIV, The AIDS Support Organization (TASO) in Uganda supported by the Population Council's Frontiers in Reproductive Health Program initiated a study in 2007 to understand the sexual and reproductive health needs of adolescents born with HIV. The study involved both survey and qualitative interviews with HIV-infected girls and boys aged 15–19 years. Its aim was to better understand the sexuality (desires, experiences, beliefs, and values) of this segment of the population, and to identify anxieties or fears they have around growing up, love and loving, dating, pregnancy, fatherhood, motherhood, relationships and intimacy. This brief describes some of the key findings from this study and discusses their programmatic implications.

### Methods

Study respondents were identified and recruited through existing HIV/AIDS treatment, care and support centers in four districts of Uganda, that is, Kampala, Wakiso, Masaka, and Jinja. Access to the client registers was granted by the management of the centers while the data officers working at the centers assisted with identifying clients falling within the desired age bracket. The counselors then helped with identifying those clients who were recorded as being perinatally infected with HIV or presumed to be so (that is, those who had been living with HIV since infancy) and to whom HIV sero-status had been disclosed.

**Table 1: Distribution of Study Respondents by Sociodemographic Characteristics**

Characteristic	Male (n = 263)	Female (n = 469)	Both genders (n = 732)
<b>Mean age (y)</b>	<b>17</b>	<b>16</b>	<b>17</b>
<b>Age, y (%)</b>			
15	35	33	34
16	14	17	16
17	8	10	9
18	25	23	24
19	18	17	17
<b>District (%)</b>			
Jinja	32	21	25
Kampala	24	29	27
Wakiso	18	35	29
Masaka	26	15	19

A total of 740 young girls and boys were identified for the survey and 732 were successfully interviewed. Female respondents comprised about two-

thirds (64%) of the study sample (Table 1). There was, however, no significant difference in the mean ages of male and female participants. Survey data were collected using a structured questionnaire in both English and either of the two other local languages, *Luganda* or *Lusoga*. A wide range of issues were covered including socio-demographic characteristics, access to sexual and reproductive health information, sexual behavior, preventive knowledge and practices, contraceptive knowledge and use, pregnancy and childbearing intentions and experiences, self-esteem, worries, and sexual and physical violence.

Another 48 young people were identified to participate in focus group discussions (FGDs) and 12 others were identified for in-depth interviews and ethnographic case stories. Seven FGDs were conducted, with each FGD having an average of six participants. In-depth interviews and case stories were conducted with all the 12 informants. Informed consent to participate in the study was sought at two levels: the parents/guardians first, followed by the individual adolescents. Parents/guardians of respondents aged 15–17 years were asked to provide written permission for their children to participate in the study. Subsequently, the respondents were asked to indicate their own willingness to participate by assenting to the study. Only individual written consent was obtained from respondents aged 18–19 years and those considered to be emancipated minors<sup>1</sup>.

## **Results**

Key findings are summarised in Table 2. Contrary to the emphasis by service providers on refraining from or postponing sexual initiation, the findings indicate that these adolescents are beginning or do desire to explore their sexuality. Of all interviewed respondents, 44% reported a desire to have sex, and 41% believed that there was no reason why someone who living with HIV should not have sexual intercourse. About 40% of all respondents had ever been in a relationship with a significantly higher proportion of male than female participants reporting having been in a relationship. In addition, 33% of the respondents reported having had sexual intercourse. Slightly more male than female respondents reported having had sex though the difference is not significant. It is also worth noting that of those who had had sex, close to three-quarters (73%) had consensual first sex, with significantly more male than female respondents reporting consensual first sex.

## **Discussion**

These patterns raise a number of questions that have implications for HIV transmission. First, what kinds of partners do young people living with HIV desire to have? Our findings show that over one-third (37%) of the respondents would prefer a partner who is HIV-negative with significantly more male than female respondents reporting such preference. Another

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<sup>1</sup> Adolescents not living under the control of parents or guardians, i.e., those who are married or are taking care of their siblings or their own children. In Uganda the National Council of Science and Technology allows emancipated minors to consent to participating in research as long as they are thoroughly informed about the risks involved.

29% indicated no preference, suggesting that the proportion of respondents who would prefer HIV-negative partners could even be higher. Indeed, of those who were currently in a relationship and knew the HIV status of the partner, 39% were in discordant relationships. The major reason given for preferring HIV-negative partners was to avoid HIV re-infection. Another interesting pattern is that significantly more female than male respondents reported no partner preference yet more female than male adolescents who knew the HIV status of the partner were in discordant relationships. This is further indication that the proportion of respondents preferring HIV-negative partners could be higher than what was reported.

The second question raised by the observed patterns is the extent to which young people living with HIV, who know their sero-status, and who are in relationships engage in safe sexual practices in order to avoid spreading the virus. The study findings show that among those who had ever had sex, only about one-third (37%) reported using a method to prevent HIV infection or re-infection at first sex with no significant difference between male and female respondents. Among current users of condoms, the proportions reporting usage to prevent infecting the partner with HIV and other sexually transmitted diseases (STDs) and to avoid self re-infection remained low. Much of current use of condoms was for pregnancy prevention. Moreover, less than half of those currently using condoms reported consistent use.

**Table 2: Percent distribution of respondents by their views about sex and sexual experiences**

	All respondents			
	Male (n=263)%	Female (n=469)%	Significance test <sup>e</sup>	Both genders (n=732)%
Ever had a boyfriend/girlfriend	46	37	*	41
Ever had sex	37	31	NS	33
Desires to have sex	55	38	**	44
HIV-positive person should have sex <sup>a</sup>	54	34	**	41
Partner preference				
• HIV-negative partner	42	34	*	37
• HIV-positive partner	35	34	NS	34
• No preference	23	32	**	29
Main reason for preferring HIV-negative partner <sup>b</sup>				
• Avoid re-infection	68	60	*	63
• Have HIV-negative children	14	13	NS	14
• Other	18	27	**	23
Worried about				
• Disclosing HIV status to friends	44	54	**	51
• Becoming pregnant/causing pregnancy	75	74	NS	74
• Infecting someone else with HIV	75	83	**	80
Sexually active respondents <sup>f</sup>				
• Had consensual first sex <sup>c</sup>	89 (n=98)	63 (n=144)	**	73 (n=242)
• Used a method to prevent HIV	35 (n=98)	39 (n=138)	NS	37 (n=236)

infection/re-infection at first sex				
• Currently using a condom to prevent <sup>d</sup>	(n= 49)	(n= 65)		(n= 114)
• Infecting partner with HIV/STDs	35	26	NS	30
• HIV re-infection	25	26	NS	25
• Pregnancy	61	54	NS	57
Frequency of current condom use	(n=49)	(n=65)		(n= 114)
• Always	45	43	NS	44
• Sometimes	33	31	NS	32
• Rarely	8	21	NS	16
• Missing	14	5	NS	9
Respondents currently in a relationship				
• Knows partner's HIV status	35 (n=63)	32 (n=96)	NS	33 (n=159)
• In discordant relationship	24 (n=21)	50 (n=30)	NS	39 (n=51)
• Disclosed HIV status to partner	42 (n=62)	35 (n=96)	NS	38 (n=158)

HIV = human immunodeficiency virus; NS = not significant; STDs = sexually transmitted diseases.

<sup>a</sup> Proportion of respondents who believed that there is no reason why a person living with HIV should not have sex.

<sup>b</sup> Participants who reported preference for HIV-negative partners. This was an open-ended question whose responses were re-coded after data entry.

<sup>c</sup> Both partners were willing or wanted to have sex.

<sup>d</sup> Multiple responses were allowed.

<sup>e</sup> Significance test of difference between male and female proportions: \*p <.05; \*\*p <.01.

<sup>f</sup> Participants who had ever had sex.

There is also evidence suggesting that risky sexual practices are affected by the disclosure of HIV status [5] though other studies have found otherwise [6]. The study findings show that disclosure of HIV status to the partner is low. Just over one-third (38%) of the respondents who were currently in a relationship disclosed their HIV status to their partners. In addition, disclosing one's sero-status was one of the greatest fears of the adolescents: 51% of all respondents feared disclosing their status to friends. Qualitative data further suggest that even in the event of disclosure, the partners do not mind engaging in the relationship even if they are discordant, as illustrated by the following examples:

*"I asked her to leave me and find someone else-negative. She told me that she was not going to leave because of my status."* (Case Study No. 7)

*"If you have a sign people may leave you alone. But if no sign, they come after you even if you tell them, they say you are lying . . ."* (FGD No. 5)

*"I have a boyfriend. He knows my HIV sero-status. I disclosed to him and he said that he did not mind."*  
(FGD No. 3)

These research findings have several implications. Of importance, the findings suggest that many of the HIV-positive adolescents are sexually active or desire to be in relationships. In addition, many prefer HIV-negative partners. However, preventive practices, including disclosing

one's HIV status to the partner, are poor. Some of these experiences apply to the general population as well [7,8]. Although not directly comparable, available Uganda data on young people aged 15–19 years who had ever had sex shows that the percentage that knew the HIV status of their partner was even lower (8% for males and 10% for females) with similar patterns being observed among adults (ages 15–49 years; 11% for males and 9% for females) [8]. Nonetheless, the case of those living with HIV is unique because they stand the greatest chance of transmitting the virus. HIV/AIDS programs therefore need to appreciate that perinatally infected adolescents have similar desires as of those of other children maturing into adolescence and adulthood. Thus, there is need to provide preventive sexual and reproductive health information and services to HIV-positive adolescents in order to prevent further HIV transmission and unwanted pregnancies. This should entail empowering these adolescents with skills to negotiate disclosure and consistent condom use.

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## Appendix 10B: Adolescent Sexual Abuse

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### The highest probability indicators of sexual abuse

As previously mentioned, in many cases of abuse, there are no physical symptoms. There are, however, some specific indications that abuse has occurred. These can include:

- Unexplained pregnancy
- Unexplained sexually transmitted infections; pain, swelling, bleeding or irritation of the mouth, genital or anal area; and urinary tract infections
- Hints, indirect comments, or statements about the abuse
- Problem sexual behaviours: Some adolescents who were sexually abused also may become sexually provocative and copy adult behaviour, displaying sexual knowledge, through language or behaviour, beyond what is normal for their age. Others merge sexual behaviour and aggression and may become the victimizers of others.

There is little dispute over the fact that some of these symptoms result from sexual activity, however, the age of the adolescent should be taken into consideration when pregnancy or sexually transmitted infections are found. In Zambia, the age of consent for sexual activity is 16 years. However, adolescents younger than 16 may have consensual sex, that is, sex in which they willingly engage. In some cases therefore, it may be necessary to make a judgement call about whether the sexual activity was forced. The younger the adolescent, the more likely it is that the activity was forced; adolescents under 12 are generally considered incapable of consenting to sexual contact. For adolescents between the ages of 12 and 16, or older, the determination of whether or not abuse occurred may require interview and clinical judgement.

### Recognising the signs and symptoms of sexual abuse in adolescents

The table below presents a checklist of physical and behavioural signs and symptoms that may be associated with sexual abuse in adolescents. This checklist is not a diagnostic tool; and these signs and symptoms may result from other causes. It is also important to remember that the absence of any signs or symptoms does not indicate that no sexual abuse has occurred. Each individual survivor reacts differently and a determination of sexual abuse cannot be based on signs or symptoms only. Behavioural signs of sexual abuse, while more common, can be indicators of other types of trauma. Therefore, even if these signs exist, it is necessary to gather more information to conclude whether or not sexual abuse has occurred.

#### Signs and symptoms associated with sexual abuse in adolescents

Physical signs	Yes	No
Difficulty walking or sitting		
Cuts and bruises		
Signs of physical abuse (for example, punch marks, restraint		

marks on the wrist, torn eardrums; all should be investigated as possible indication of physical and/or sexual abuse)		
Complaints of pain with urination or bowel movements		
Irritated or itching genitals or anus		
Bleeding from the genital area or anus		
Urinary tract infection, blood in urine, or difficulty with urination		
Vaginal or penile discharge		
Pregnancy (younger than 16)		
Sexually transmitted infection, warts, ulcers in genital area		
Unusual and offensive odours from genital area or anus		
Fresh or healed tears of the hymen or vaginal mucosa		
Developing frequent, unexplained health problems		
<b>Changes in behaviour</b>	<b>Yes</b>	<b>No</b>
<b>Nonsexual indicators</b>		
Avoidance of specific caregivers or caregiving situations		
Sleep disturbances, such as nightmares or bedwetting in younger adolescents		
Withdrawal from family, friends, or usual activities		
Unexplained fear of physical or gynecologic examination		
Significant increase or decrease in appetite (eating disorders)		
Excessive bathing or poor hygiene		
Reluctance to be with a certain person		
Mood changes, such as anger, outbursts, or depression		
Becoming worried when clothing is removed		
Academic problems		
Lowered self-esteem		
Symptoms of post-traumatic stress disorder, such as panic attacks		
Excessive crying		
<b>Sexual indicators</b>		
Age-inappropriate knowledge of sex		
Imitating sexual acts or copying adult sexual behaviour with younger children, toys, or pets		
Excessive masturbation		
Sexual experimentation with age-inappropriate partners		
<b>Note: This is not a diagnostic tool; these signs and symptoms may result from other causes.</b>		

Additional signs of sexual abuse that may be present in older adolescents include:

- Drug and alcohol use
- Delinquency
- Running away
- Depression
- Early sexual involvement/activity
- Promiscuity
- Criminal activity

- Self-destructive behaviour (for example, suicide attempts or self-mutilation)
- Eating disorders (anorexia/bulimia)

As adolescents mature, they become aware of societal responses to their sexual activity, and therefore overt sexual indicators of the type cited in the table above are less common. Moreover, some level of sexual activity is considered normal for adolescents. However, there are three sexual indicators that *may* signal sexual abuse:

- Sexual promiscuity among girls
- Being sexually victimized by peers or nonfamily members among girls, that is, repeated victimization when a adolescent is older may be evidence of earlier unrecognised sexual abuse
- Adolescent prostitution

Of these three indicators, the last is most compelling. One study found that 90 percent of female adolescents involved in sex work were sexually abused at some point in their lives<sup>2</sup>. Although there has not been comparable research on adolescent male sex work<sup>3</sup>, clinical observation suggests that they also become involved in the exchange of sexual services for goods or money as a result of sexual abuse.<sup>4</sup>

### **Interviewing an adolescent who may have been sexually abused**

Talking about sexual abuse is extremely difficult for most adolescents. They are afraid, may feel embarrassed or ashamed, and often do not know how to talk about what has happened to them. Sometimes they have been bribed, threatened, or made to feel responsible for their abuse. The ideal location to interview an adolescent about sexual abuse is in a quiet, comfortable, and private setting, either alone or with an adult of her or his choice. Sit at the adolescent's level and use the listening and learning skills described in Module 4.

Be very patient and take plenty of time. Keep in mind that if a young person is feeling defensive, they are not feeling safe. Do not push and prod. Stay as calm as possible. Adolescents often stop talking if they think that what they are saying makes you upset<sup>5</sup>. Adolescents are also more likely to give an answer that they think the questioner wants to hear. It is therefore important when asking questions not to appear to lead the adolescent to answer the question with a particular answer, but rather encourage the adolescent to be open and honest.

<sup>2</sup>.Faller, K.C. 1990. *Understanding Child Sexual Maltreatment*. Newbury Park, CA: Sage.

<sup>3</sup> Please note that UNAIDS Editors' Notes for authors (August 2006) preferred the term juvenile prostitution for this group.

<sup>4</sup> Campagna, D. and Poffenberger, D. 1988. *Sexual Trafficking in Children*. Dover, MA: Auburn House.

<sup>5</sup> Adapted from: Prevent Child Abuse NY. Available at: <http://www.preventchildabuseny.org/resources/about-child-abuse/>

Be careful not to plant ideas in the adolescent's mind or to suggest what you expect to hear. Above all, reassure the adolescent that the abuse was not her or his fault. There is nothing that she or he did to deserve what happened. Help young people understand that it is all right to feel angry, and help them express their anger in ways that are healthy for themselves and others.

Healthcare workers will get further — and get a more accurate account — if they ask open-ended questions. (An open-ended question requires an explanation/description for an answer, rather than a simple yes/no one word answer.) For example, rather than asking, “*That man touched you on your private parts didn't he?*” it would be better to ask, “*Tell me about what happened when you were out with that man*” As a general rule, healthcare workers should not ask questions that start with “why”, as such questions may come across as accusatory. See Module 4 for more information on open-ended questions.

### **How to begin questioning related to suspected sexual abuse<sup>6</sup>:**

Always introduce the principle of shared confidentiality and explain your obligations as a healthcare worker, should disclosure of sexual abuse occur during the conversation.

Try to make the adolescent comfortable by explaining that you would like to ask her or him some questions. Explain that she or he should be honest and should not be afraid. Begin by first normalizing the topic. For example: “*Because I want to help my clients, I ask everyone about questions that may be sensitive. It is important that I know some things in order to help you.*”

Begin the interview with open-ended questions. Ask questions in a non-judgemental way. Avoid technical or medical language:

- *It looks like something might be bothering you. Can you tell me about it? I'd like to know more about this.*
- *Can you tell me about if someone ever touched you in a way you didn't like? How did they touch you?*
- *Has someone ever hurt you or made you feel bad? How so?*
- *Has someone ever touched your private areas? Where?*
- *What happened?*
- *Tell me more.*
- *When was last time this happened?*

For older adolescents:

- *How long have you been sexually active?*
- *Has anything ever happened sexually with a friend, a date, or someone you know that you didn't like? Were you ever pressured or forced you into*

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<sup>6</sup> Adapted from: United States Department of Health and Human Services, Administration of Children and Families. Available at: <http://www.childwelfare.gov/pubs/usermanuals/sexabuse/sexabusec.cfm>

*sexual activities when you did not want them? Touched you in a way that made you uncomfortable? Anyone at home? Anyone at school? Any other adult?*

- *Do you feel that you have control over your sexual relationships and will be listened to if you say “no” to having sex?*

Other possible questions for younger adolescents include:

- *Did you ever see an adult’s private parts? Whose did you see?*
- *Did anyone ever ask you to touch their private parts? Who?*
- *Did anything ever happen to your private parts that you didn’t like? What?*

Always validate the adolescent’s response:

- *Thank you for telling me about such a difficult experience.*
- *I’m sure that was hard for you to tell me. It is good that you told me.*
- *When someone hurts you, it is devastating in many ways. Let’s talk about some of the ways you need support.*

Evaluate and follow up

- Immediately evaluate present-day level of danger, other violence, drug and alcohol use, and health habits. Mention their disclosure again during another visit and continue to ask about his/her needs. Request a 1- to 2-week follow-up appointment with the adolescent.

### **Other clinical follow up after the interview**

If an adolescent discloses sexual abuse in the interview, a thorough physical and gynaecological examination (procedures described in Module 10) should be conducted by a healthcare worker, with the adolescent’s consent.

Respect for privacy during physical examinations is imperative for adolescents who have experienced sexual abuse. Healthcare workers have an excellent opportunity to demonstrate this respect and to help the adolescent regain a sense of control over his/her body by draping the adolescent and allowing them to stop the examination if they feel uncomfortable at any time. Healthcare workers should also model sensitive, respectful physical examination techniques to other members of the clinical team.

For all individuals without confirmed HIV infection, healthcare workers should follow national HIV testing guidelines in “Adult and Adolescent Antiretroviral Therapy Protocols, 2010” and the PEP protocol in “Adult and Adolescent Antiretroviral Therapy Protocols”.

### **Follow up for psychosocial and mental health issues**

Adolescents need support to deal with what happened to them and to discharge and cope with their feelings. Healthcare workers can make referrals to peer support groups or local community-based services that have experience dealing with youth who have been sexually abused.

At a minimum, healthcare workers should conduct a psychosocial assessment to determine the impact of the abuse on the adolescent, level of family support to assist with coping, and the ability and willingness of the family to ensure the adolescent's continuing safety. The initial assessment should be accompanied by some mental health intervention to reduce the immediate impact of the trauma. There should also be a discussion with the adolescent, or with the caregiver if the adolescent is too young to understand and if the caregiver is not the perpetrator of sexual violence, of what to expect from the adolescent after the abuse. Helping the adolescent and caregiver understand what behaviours and emotions are likely to follow the abuse, and assisting them in understanding that these are a natural result of the abuse, will help them to cope more effectively with the impact of the abuse.

National policy recommends follow up for assessment and treatment of mental health issues at 7 days, 1, 2, 3 and 6 months after the abuse. Healthcare workers should be knowledgeable of the resources available within the facility and within the community to treat the adolescent. If the facility does not have the capability to provide mental health services, the adolescent should be referred to a facility that has mental health resources. For more information about assessment and treatment of mental health problems and disorder, refer to Module 6.

### **Legal follow up**

Healthcare workers must understand any relevant laws and report cases of sexual abuse, according to these laws.

The Victim Support Unit, part of the law enforcement division of police services, is required by law to be notified of suspected cases of abuse or neglect of adolescents under the age of 16 years. This department is responsible for working with representatives from social welfare and health services as part of a multidisciplinary team. Their duties include the investigation of the report, determination of whether abuse has occurred, to ensure the continued safety of the adolescent, and to prosecute the person who committed the abuse. Because sexual abuse is a criminal offense, healthcare workers may be responsible for reporting findings in a court of law. It becomes vital, therefore, for healthcare workers who have had contact with the adolescent or with evidence gathered from the adolescent to maintain the chain of evidence; that is, collecting, storing, and documenting all the gathered material for possible presentation in court proceedings.

## Appendix 10C: Screening and Examining Adolescent Clients for STIs

Screening questions	Physical examination steps
<b>For adolescent women:</b>	
<ul style="list-style-type: none"> <li>Do you have vaginal discharge that is not normal for you (colour, amount, smell)?</li> <li>Do you have any pain when you urinate (pee)?</li> <li>Do you have any sores or bumps in or around your genitals?</li> <li>Do you have any pain in your lower abdomen?</li> </ul>	<p>Ask the young woman to undress from the waist down and lie on an exam table, or if she is wearing a skirt, she can leave it on and take off her underpants. Be sure to cover her with a sheet and only expose the parts that you examine.</p> <p><b>External exam:</b></p> <ul style="list-style-type: none"> <li><b>Skin exam:</b> inspect the skin of the genitals, perineum, inguinal areas, thighs, lower abdomen, buttocks, chest, back, soles of feet and palms of hands. Look for vesicles, ulcers, warts, other growths, and rashes.</li> <li><b>External genital exam:</b> Inspect and palpate the external genitalia, then inspect the perineum and anus. Look for ulcers, vesicles, warts, and discharge.</li> <li><b>Inguinal exam:</b> Examine the inguinal area and palpate for lymph nodes.</li> <li><b>Abdominal exam:</b> Palpate the abdomen, checking for guarding, tenderness, rebound tenderness, and masses.</li> </ul> <p><b>Internal exam</b></p> <ul style="list-style-type: none"> <li><b>Internal genital exam:</b> Have the woman lie with her legs bent at the knees, keeping her feet and knees separated. Separate the labia and insert a bivalve speculum* lubricated with warm water. With a bright light shining on the area, inspect the vaginal walls and the cervix. Look for ulcers, warts, and cervical and vaginal discharge.</li> <li><b>Bimanual pelvic exam:</b> Remove the speculum and insert the lubricated index and middle fingers of your hand into the vagina. Place your other hand on the lower abdomen and examine the pelvis for swelling and tenderness. Move the cervix laterally and check for cervical motion tenderness. Check for tenderness and masses around the uterus and ovaries.</li> </ul> <p>* Some healthcare workers prefer to not use the speculum, or to use a smaller speculum, in women who are virgins.</p>
<b>For adolescent men:</b>	
<ul style="list-style-type: none"> <li>Do you have any discharge from your penis?</li> <li>Do you have any pain when you urinate?</li> <li>Do you have any sores or bumps around your genital area or your anus?</li> </ul>	<p>Ask the man to undress from the waist down and lie on an exam table. Be sure to cover him with a sheet and only expose the parts that you examine.</p> <ul style="list-style-type: none"> <li><b>Skin exam:</b> Inspect the skin of the genitals, perineum, anus, inguinal areas, thighs, lower abdomen, buttocks, chest, and back, soles of feet, and palms of hands. Look for vesicles, ulcers, warts, other growths, and rashes.</li> <li><b>External genital exam:</b> Inspect the penis, including the opening of the urethra, by retracting the foreskin. Look for ulcers, vesicles, and urethral discharge. If the patient complains of discharge and none is present, give the urethra</li> </ul>

	<p>a gentle squeeze and massage it forward to try and express any discharge. Inspect in and around the anus. Palpate the scrotal contents and note presence of ulcers or buboes.</p> <ul style="list-style-type: none"><li>• <b>Inguinal examination:</b> Palpate the groin, feeling for enlarged lymph nodes and the presence of buboes.</li></ul>
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Zambia Ministry of Health, *National STI Syndromic Case Management Guidelines for Zambia*.

# Appendix 10D: Survey of Family Planning Methods for Adolescents

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## Barrier Methods

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### Male and female condoms

- Only condoms provide protection from both pregnancy and STI (including HIV) transmission and acquisition.
- Male and female condoms are highly effective when used consistently and correctly every time.
- In real-life situations, and especially among adolescents, correct and consistent condom use may be difficult to achieve. Partner involvement is required. Some people — more often men than women — report diminished sensation when using condoms during sex.
- Condom use does not interfere with medications, however, and except when an individual is allergic to latex, there are no common side effects for male and female condoms.
- **Special considerations for the adolescent client:** Male and female condoms are safe and appropriate for ALHIV. Because condoms are available without a prescription and are the only method offering dual protection, they are a good method for adolescents. It is important that condoms are always available to adolescents for free and without having to ask an adult for supplies. Adolescents require skill development and practice in learning how to use condoms and negotiate their use with sexual partner(s). Adolescent girls are frequently not assertive about the use of condoms if their partner rejects the idea; they require counselling and peer support to feel empowered and able to negotiate condom use and overcome cultural and other barriers. Consistent and correct condom use is effective in providing dual protection, but failure rates (i.e. unintended pregnancy) for condoms are high, especially among adolescents, who often do not use them consistently or correctly.
- **Counselling the adolescent client about condoms:** Always demonstrate, step-by-step, how condoms are used and correct disposal. Tell the client to return to the clinic if there is any problem, they need more condoms, if they are unhappy with the method, or if they think they or their partner may have been exposed to an STI. Always ask the adolescent client to repeat the instructions to ensure understanding.

## **Spermicides and diaphragms with spermicides**

- These methods are NOT recommended for adolescents or adults living with HIV, as they may increase the risk of HIV transmission.

## **Hormonal Methods**

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Hormonal contraceptives, including combined oral contraceptive pills (COCs), progestin-only oral contraceptive pills (POPs), emergency contraceptive pills (ECP), injectables, and implants are appropriate and effective contraceptive methods for many ALHIV. They are generally easy to use, are suitable for short- and long-term use, are reversible, and provide noncontraceptive health benefits.

### **COCs and POPs:**

- These are pills that a woman takes once a day to prevent pregnancy.
- They contain the hormones oestrogen and progestin (in the case of COCs) and progestin alone (in the case of POPs).
- Both types are very effective at preventing pregnancy when taken on schedule.
- **Special considerations for the adolescent client:** Low-dose COCs are appropriate and safe for ALHIV. Many adolescents choose a COC because of the low failure rate, relief from painful periods, and the ease of using a method that is not directly related to sex. Failure rates for COCs are higher for adolescents than for all other age groups. Failure to take pills at the same time, every day, is often due to lack of knowledge or confusion about how to take pills. Healthcare workers should stress that COCs can prevent pregnancy but should always be used in combination with condoms to provide STI/HIV protection. Healthcare workers can assist adolescent clients to determine where they will keep their pills and how to remember to take them at the same time every day, similar to their ARVs. COCs are available in 21- or 28-day regimens. Most adolescents do better with the 28-day regimens because it is easier to remember to take a pill every day rather than stopping for 7 days.

COCs should not be taken by clients taking rifampicin for TB treatment.

ARVs may adversely affect the efficacy of low-dose COCs and/or increase their side effects. Women taking ARVs who want to use COCs can be given a formulation with at least 30mcg of oestrogen, counselled about the importance of taking COCs on time every day (without missing pills), and counselled about consistent condom use.

POPs are also safe for adolescents, but since they must be taken at exactly the same time everyday for them to be effective in preventing pregnancy, they may not be the best choice for adolescents. POPs may

however be a good choice for adolescents who cannot tolerate estrogen in COCs or who are breastfeeding.

- **Counselling the adolescent client about oral contraceptive pills:**  
The most important counselling issue with adolescents is to make sure they understand the importance of taking pills correctly. Show the client the pill packet and explain in detail when to start taking pills and how to take the pills. Explain that if she forgets to take her pills, she may become pregnant. Instruct the client on what to do if she misses pills (for example, if she misses one, take it as soon as she remembers, if she misses 2, take 2 pills as soon as she remembers and use a back up method, etc.). Always review possible side effects, including that breakthrough bleeding may be common in the first cycles, but is not a reason to stop taking the pills. Like with ARVs, the client should be encouraged to talk with a healthcare worker about any side effects (nausea, weight gain, breast tenderness, headaches, spotting, etc.) and told that these will usually settle over time. Go over the times when she should return to the clinic, including if she thinks she may be pregnant, she has chest pain or shortness of breath, severe headaches with blurred vision, and swelling or severe leg pain. Make sure the client understands when to come back for re-supply and not to wait until she is out of pills (like with ARVs). Always have the client repeat information back to you so you can check understanding. And always promote dual protection with male or female condoms.

### **Injectables:**

- Progestin-only injectable contraceptives, such as Nur-Isterate and Depo-Provera (depot medroxyprogesterone acetate, aka DMPA and 'the shot'), contain no estrogen.
- To prevent pregnancy, a shot is given to the woman in the arm or upper buttock every 2–3 months, depending on the type of injectable.
- Injectables are highly effective when used correctly.
- ALHIV can use progestin-only injectables without restrictions. Adolescents on ART can also use progestin-only injectables safely and effectively.
- It is important to counsel adolescents to come for their next injection on time and without delay.
- Side effects of injectables may include spotting at first, then amenorrhea and weight gain.
- Special considerations for the adolescent client: Injectables are safe and appropriate for adolescents. Many adolescents like this method because they don't have to remember to take a contraceptive pill every day and no one needs to know they are using the method. It is important that adolescents are reminded when to return for their injections, ideally this can be combined with their routine HIV care appointments.
- Injectables do not offer protection from STIs/HIV, so should always be used with male or female condoms.

- **Counselling the adolescent client about injectables:** Healthcare workers should show their clients the vial of the injectable and explain how it is used. It is important to stress that the injections need to be given every 3 months and that injections can be given early if a client thinks she will not be able to return at the 3 month point. The injection will take effect immediately if she is between day 1–7 of her menstrual cycle. If the injection is given after day 7 of her cycle, she should use a back-up method for at least 24 hours. It is important for adolescents to understand possible side effects, which include irregular bleeding and prolonged light to moderate bleeding with the first few cycles of injectables. With time, this should stop and many women stop getting their menstrual cycle altogether while using injectables. Some woman may also have weight gain or headaches. Healthcare workers should encourage clients to return to the clinic if they have any questions or problems or if they have very heavy bleeding, excessive weight gain, or severe headaches. Make sure the client repeats this information back to you to check understanding. As with all hormonal methods, healthcare workers should recommend and provide condoms for dual protection.

### **Hormonal implants:**

- Progestin-only implants (eg, Implanon, Norplant) consist of up to 6 hormone-filled, matchstick-like rods, which are inserted under the skin in a woman's upper arm.
- Hormonal implants can prevent pregnancy for between 3 and 7 years, depending on the type.
- Highly effective at preventing pregnancy, implants are a long-term contraceptive method that can be easily reversed.
- ALHIV who do not take ART can use progestin-only implants without restrictions. ALHIV on ART can also use progestin-only implants, but should use condoms as a back-up method in the event that the effectiveness of the implant is reduced by ARVs.
- Side effects of implants may include nausea, weight gain, and changes in monthly bleeding. As with all hormonal methods, women should also be encouraged to use condoms for dual protection.
- **Special considerations for the adolescent client:** Hormonal implants, such as Norplant, are safe for adolescents. The main reason adolescents discontinue using implants is irregular bleeding; counselling is important so they are prepared for this possibility. Programmes must ensure that adolescents have access to services to remove implants whenever they need or want them to be removed.
- **Counselling the adolescent client about implants:** Healthcare workers at the HIV clinic will likely have to refer adolescents to a family planning clinic for implant insertion and removal. It is important to explain how the implants work, what the insertion and removal

procedures are, and how long the method will last. Adolescents should also be counselled on care of the insertion area and possible bruising or swelling after insertion. Adolescents should know where to go if they have problems or questions, or if they want the implants removed. Healthcare workers should give information on common side effects, such as changes in bleeding, as well as serious problems requiring immediate care such as severe pain in the lower abdomen, very heavy bleeding, bad headaches, and yellowing of the skin or eyes.

### **Emergency contraceptive pills (ECP):**

- ECP is used to prevent pregnancy after unprotected sex.
- ECP can be used if no contraceptive method was used, or if the contraceptive method failed — for example, a condom broke during sex.
- ECP should be taken as soon as possible after unprotected sex (although it can be taken up to 120 hours after sex).
- Used correctly and in timely fashion, ECP can reduce the risk of pregnancy by 75%.
- ECP is usually a combination of oral contraceptives taken in 2 doses.
- ECP does not cause an abortion. It prevents an egg from implanting in the uterine wall.
- ECP is safe for all women, including those living with HIV and those taking ART.
- Side effects of ECP may include nausea, vomiting, and changes in the menstrual cycle.
- Adolescents receiving ECP should be counselled on adopting a regular contraceptive method, as well as on condom use for dual protection.
  
- **Special considerations for the adolescent client:** ECP should be widely and easily available to adolescents, including at the HIV clinic. Adolescents should be educated about the availability of ECP and the importance of coming to the clinic for ECP as soon as possible after unprotected sex. The earlier ECPs are taken after unprotected sex, the more effective they will be in preventing pregnancy. ECPs can be provided in advance to adolescents who are at high-risk of unprotected sex, but they should be counselled that ECPs are for emergency use only. ECPs do not provide dual protection and all adolescents using ECPs should be counselled on more effective contraceptive methods and condom use for dual protection.
  
- **Counselling the adolescent client on ECP:** Healthcare workers should explain how ECPs work and how the adolescent should take them (for example, the first dose should be taken as soon as possible after unprotected sex, up to 120 hours after unprotected sex, the second dose should be taken 12 hours after the first dose). If more than 120 hours have passed since unprotected sex, the client should not be given ECP. If the client vomits within 2 hours of taking a dose, the dose should be repeated. Taking the doses after eating or before bed will

help reduce nausea. Healthcare workers should review what adolescents can expect after taking ECPs — they may have nausea, vomiting, cramping, breast tenderness, or headaches, but these should not last more than 24 hours. The adolescent's period should come on time (or a few days late or early), and if she does not get her period within one week of when it is expected she should return to the clinic as she may be pregnant.

## **Long-term and Permanent Methods**

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### **Intra-uterine devices (IUDs):**

- This small device inserted into a woman's uterine cavity is highly effective at preventing pregnancy.
- The copper-containing CuT 380A — the most commonly used IUD — remains effective for up to 12 years.
- An IUD can be provided to a woman living with HIV if she has no symptoms of AIDS and no STIs. A woman who develops AIDS while using an IUD can continue to use the device. A woman with AIDS who is doing well clinically on ART can both initiate and continue IUD use but may require follow up.
- An IUD generally should not be initiated in a woman with AIDS who is not taking ART.
- Side effects of IUDs may include heavy bleeding and pain during the first months of use, as well as spotting.
- Encourage women choosing an IUD to use condoms for dual protection.
- **Special considerations for the adolescent client:** IUDs are appropriate for adolescents in stable, mutually monogamous relationships. Careful screening for STIs before insertion is critical and IUDs are not recommended for ALHIV with advanced HIV disease or AIDS, especially when the client is not on ART.
- **Counselling the adolescent client about IUDs:** It is important to explain that the IUD is a long-term method that lasts for 10–12 years and that it is most appropriate for adolescents who are in stable, monogamous relationships. Healthcare workers may have to refer adolescent clients for IUD insertion, but should provide counselling and follow up within the HIV clinic. It is important for adolescent clients to understand how the IUD works and how to check for the strings. Healthcare workers should explain side effects, including cramping and pain after insertion, heavier and longer menstrual flow for the first few months, vaginal discharge, and possible infection. Bleeding usually decreases during the first and second years of IUD use, and some women may not have regular periods. Adolescents should know the warning signs of potential complications with IUDs, including abnormal bleeding and discharge, pain, pain during sex, fever, and strings missing/shorter/longer. Make sure the client repeats this information to

ensure understanding. It is very important to use condoms to prevent STIs, which can cause infection and complications, especially when using an IUD.

### **Male and female sterilisation**

- These permanent methods are not usually recommended for adolescents, who may change their mind about wanting to have children in the future.
- However, some ALHIV may request sterilisation, in which case counselling should be provided and all options explored.

### **Traditional and Other Methods**

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**Natural methods** that do not require any materials (i.e. withdrawal, a woman learns to recognise when she is fertile and the couple avoids sex at this time.). In general, natural methods are not as effective in preventing pregnancy as the other “modern” methods. In some places, there are **traditional methods**. These are mostly traditional herbs that are given to prevent pregnancy. They are not reliable, because the dosage is not controlled and they are not scientifically proven.

### **Lactational amenorrhea method (LAM):**

- LAM is a temporary, natural contraceptive option for women who are less than 6 months postpartum, who are exclusively breastfeeding, and whose periods have not yet returned.
- Any clients practising LAM should be advised to use condoms for dual protection.
- Most adolescents will not be breastfeeding (unless they have infants), so this is not a likely option for ALHIV.

### **Fertility awareness methods:**

- These methods require a woman to identify the fertile days of her menstrual cycle and to abstain from sex during these times.
- To do so, she can observe fertility signs, such as the consistency of her vaginal mucus, or she can follow the calendar.
- This is a difficult method for many adolescents to implement correctly and consistently. It is also not very reliable for pregnancy prevention and does not protect against STIs and HIV.
- Encourage ALHIV to use condoms as dual protection, especially during fertile days, or to abstain.
- Also counsel on the availability of more reliable contraceptive methods, emphasizing the importance of using condoms for dual protection.

Adapted from: Senderowitz, J., Solter, C., & Hainsworth, G. 2002, revised 2004. *Comprehensive Reproductive Health and Family Planning Training Curriculum: Module 16: Reproductive Health Services for Adolescents, Unit 7*. Watertown, MA: Pathfinder International.



## Trainer Tools for Exercise 2: Word and Definition Cards

**Instructions to the trainer:** Make enough copies so that each small group will have one complete set. Cut along dashed lines to make sets of 42 cards (or more if you have added local terms) — 21 word cards and 21 definition cards. Carefully shuffle the cards so that they are not in order.

Sex (verb)	Includes activities such as inserting the penis or fingers into the vagina or anus; kissing a partner's penis, vagina or anus; and masturbation.
Sex (noun)	The physiological attributes that identify a person as male or female (genital organs, predominant hormones, ability to produce sperm or ova, ability to give birth, etc.)
Vaginal sex	When the penis or fingers go into the vagina.
Anal sex	When the penis or fingers go into the anus.
Oral sex	When a person kisses or licks their partner's penis, vagina, or anus.
Sexuality	All the feelings, thoughts, and behaviours of being a girl or boy, including being attractive, being in love, and being in relationships that include sexual intimacy.



Body image	How we look and feel about ourselves, and how we appear to others.
Gender roles	The way we express being either male or female, and the expectations people have for us based on our sex.
Relationship	The ways we interact with others and express our feelings for others.
Intimacy	Sharing thoughts or feelings in a close relationship, with or without physical closeness.
Love	Feelings of affection and how we express those feelings for others.
Sexual arousal	The different things that excite us sexually.
Social roles	How we contribute to and fit into society.
Genitals	The parts of our bodies that define our sex (male or female). They are part of sexual pleasure and reproduction.



Gender	Refers to widely shared ideas and norms about women and men, including common beliefs about what characteristics and behaviour are “feminine” or “masculine.”
Heterosexuality	The sexual orientation in which a person is physically attracted to people of the opposite sex
Homosexuality	The sexual orientation in which a person is physically attracted to people of the same sex
Bisexuality	The sexual orientation in which a person is physically attracted to members of both sexes
Transvestism	When a person dresses and acts like a person of the opposite gender.
Transsexual	A person who desires to change, or has changed, his or her biological sex because his or her body does not correspond to his or her gender identity.
Transgendered	A person who lives as the gender opposite to his or her anatomical sex (for example, a male living as a female but retaining his penis and sexual functioning).
Other (write in)	



## Trainer Tools for Exercise 3: Sexual Behaviour Cards

**Instructions to the trainer:** Make enough copies so that each participant can have about 10 sexual behaviour cards, there are 24 cards below. For example, if you have 20 participants, then make 8 copies so that you have a total of 192 cards, which means that each participant will get 9 or 10 cards. Cut along dashed lines.

<p style="text-align: center;"><b>VAGINAL SEX</b></p> <p>OK for me    Not OK for me    Not OK but OK for Others</p>	<p style="text-align: center;"><b>2 MEN HAVING SEX</b></p> <p>OK for me    Not OK for me    Not OK but OK for Others</p>
<p style="text-align: center;"><b>2 WOMEN HAVING SEX</b></p> <p>OK for me    Not OK for me    Not OK but OK for Others</p>	<p style="text-align: center;"><b>GETTING PAID FOR SEX</b></p> <p>OK for me    Not OK for me    Not OK but OK for Others</p>
<p style="text-align: center;"><b>HAVING MANY SEX PARTNERS</b></p> <p>OK for me    Not OK for me    Not OK but OK for Others</p>	<p style="text-align: center;"><b>SEX WITH SOMEONE WHO IS MUCH OLDER</b></p> <p>OK for me    Not OK for me    Not OK but OK for Others</p>
<p style="text-align: center;"><b>SEX WITH SOMEONE WHO HAS HIV</b></p> <p>OK for me    Not OK for me    Not OK but OK for Others</p>	<p style="text-align: center;"><b>SEX BEFORE MARRIAGE</b></p> <p>OK for me    Not OK for me    Not OK but OK for Others</p>
<p style="text-align: center;"><b>HAVING SEXUAL DESIRES ABOUT SOMEONE OTHER THAN YOUR PARTNER</b></p> <p>OK for me    Not OK for me    Not OK but OK for Others</p>	<p style="text-align: center;"><b>HAVING CASUAL SEX WITH CONDOMS</b></p> <p>OK for me    Not OK for me    Not OK but OK for Others</p>
<p style="text-align: center;"><b>HAVING DRY SEX</b></p> <p>OK for me    Not OK for me    Not OK but OK for Others</p>	<p style="text-align: center;"><b>HAVING SEX WITHOUT PLEASURE</b></p> <p>OK for me    Not OK for me    Not OK but OK for Others</p>



<p><b>HAVING SEX WITH SOMEONE OF A DIFFERENT ETHNIC GROUP</b></p> <p>OK for me    Not OK for me    Not OK but OK for Others</p>	<p><b>HAVING SEX IF YOU ARE LIVING WITH HIV</b></p> <p>OK for me    Not OK for me    Not OK but OK for Others</p>
<p><b>HAVING SEX AFTER DRINKING ALCOHOL</b></p> <p>OK for me    Not OK for me    Not OK but OK for Others</p>	<p><b>MASTURBATING ALONE</b></p> <p>OK for me    Not OK for me    Not OK but OK for Others</p>
<p><b>MASTURBATING WITH YOUR PARTNER</b></p> <p>OK for me    Not OK for me    Not OK but OK for Others</p>	<p><b>ORAL SEX</b></p> <p>OK for me    Not OK for me    Not OK but OK for Others</p>
<p><b>ANAL SEX</b></p> <p>OK for me    Not OK for me    Not OK but OK for Others</p>	<p><b>BEING CELIBATE</b></p> <p>OK for me    Not OK for me    Not OK but OK for Others</p>
<p><b>BEING FAITHFUL TO 1 PARTNER</b></p> <p>OK for me    Not OK for me    Not OK but OK for Others</p>	<p><b>SEX BETWEEN A TEACHER AND A STUDENT</b></p> <p>OK for me    Not OK for me    Not OK but OK for Others</p>
<p><b>BEING ATTRACTED TO BOTH MEN AND WOMEN</b></p> <p>OK for me    Not OK for me    Not OK but OK for Others</p>	<p><b>DRESSING LIKE SOMEONE OF THE OPPOSITE SEX</b></p> <p>OK for me    Not OK for me    Not OK but OK for Others</p>



## References and Resources

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<sup>1</sup> de Bruyn, M., 1999. *Young Lives at Risk. Adolescents and Sexual Health*. Panos Briefing No. 35, London: Panos Institute London.

<sup>2</sup> Senderowitz, J., Solter, C., & Hainsworth, G. 2002, revised 2004. *Comprehensive Reproductive Health and Family Planning Training Curriculum: Module 16: Reproductive Health Services for Adolescents, Unit 6*. Watertown, MA: Pathfinder International.

<sup>3</sup> Senderowitz, J., Solter, C., & Hainsworth, G. 2002, revised 2004. *Comprehensive Reproductive Health and Family Planning Training Curriculum: Module 16: Reproductive Health Services for Adolescents, Unit 8*. Watertown, MA: Pathfinder International.

<sup>4</sup> Senderowitz, J., Solter, C., & Hainsworth, G. 2002, revised 2004. *Comprehensive Reproductive Health and Family Planning Training Curriculum: Module 16: Reproductive Health Services for Adolescents, Unit 5*. Watertown, MA: Pathfinder International.

<sup>5</sup> Senderowitz, J., Solter, C., & Hainsworth, G. 2002, revised 2004. *Comprehensive Reproductive Health and Family Planning Training Curriculum: Module 16: Reproductive Health Services for Adolescents, Unit 7*. Watertown, MA: Pathfinder International.

<sup>6</sup> Senderowitz, J., Solter, C., & Hainsworth, G. 2002, revised 2004. *Comprehensive Reproductive Health and Family Planning Training Curriculum: Module 16: Reproductive Health Services for Adolescents, Unit 7*. Watertown, MA: Pathfinder International.



# Module 11 Community Linkages and Adolescent Involvement



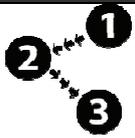
**Total Module Time:** 165 minutes (2 hours, 45 minutes)

## Learning Objectives

**After completing this module, participants will be able to:**

- Discuss common challenges and strategies to creating strong facility-community linkages in support of ALHIV and their caregivers.
- Describe community-based support services that ALHIV and their caregivers may need.
- Create a community resource directory for adolescent clients and caregivers.
- Describe the rationale for meaningful adolescent involvement and effective strategies to involve adolescents in service delivery.
- Understand the key components to implementing a successful adolescent Peer Educator programme.

## Methodologies



- Interactive trainer presentation
- Large group discussion
- Guest speaker(s) (optional)
- Small group work

## Materials Needed



- Slide set for module 11
- Flip chart and markers
- Tape or Bostik
- Copies of any community-facility referral forms used at the health facility
- Copies of any existing directories of community- and clinic-based youth and HIV-related services in the district/community
- Participants should have their Participant Manuals. The Participant Manual contains background technical content and information for the exercises.

## References and Resources



- Colton, T., Costa, C., Twyman, P., Westra, L., and Abrams, E. 2009. *Comprehensive Peer Educator Training Curriculum, Version 1.0.* International Center for AIDS Care and



	<p>Treatment Programs.</p> <ul style="list-style-type: none"><li>• Colton, T., Costa, C., Twyman, P., Westra, L., and Abrams, E. 2009. <i>Planning, Managing and Monitoring Peer Educator Programs: An Implementation Manual, Version 1.0.</i>, International Center for AIDS Care and Treatment Programs.</li><li>• Colton, T. 2010. <i>Improving Psychosocial and Adherence Counseling and Support in PMTCT Programs: A Training Curriculum for Counselors and Social Workers.</i> International Center for AIDS Care and Treatment Programs and South to South HIV Comprehensive Partnership.</li></ul>
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### Advance Preparation



- Read through the entire module and ensure that all trainers are prepared and comfortable with the content and methodologies.
- Trainers may want to invite guest speakers from the community, such as support group leaders, youth group leaders, home-based care organisation leaders or experienced staff from income-generation, vocational support, food support, or legal aid organisations. Take time to brief guest speakers: provide them with an overview of the training, describe the participants and participant expectations, let them know how much time they will have for their presentation and what they should cover in that presentation. One challenge with guest speakers is that they typically over-prepare because they want to do a good job, but then take more time than allocated. Consider how you might handle this eventuality, should it occur.
- Obtain copies of the forms used by a local agency to refer adolescent clients to a community-based or other agency
- Collect copies of any existing community HIV support resource directories or materials that are available. In many places, the district HIV teams or local NGOs will have created these directories. Try to get enough copies for each participant.
- Review the appendices so that you can refer to them and integrate them into your presentation.

### **Session 11.1: The Importance of Facility-Community Linkages**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation, large group discussion, and optional guest speaker(s)	30 minutes
Questions and answers	5 minutes
Total Session Time	35 minutes

### **Session 11.2: Creating a Community Resource Directory**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation and large group discussion	10 minutes
Exercise 1: Creating a Community Resource Directory: Small group work and large group discussion	60 minutes
Questions and answers	5 minutes
Total Session Time	75 minutes

### **Session 11.3: Adolescent Participation and Peer Education Programmes**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation and large group discussion	40 minutes
Questions and answers	5 minutes
Review of key points	10 minutes
Total Session Time	55 minutes

## Session 11.1      The Importance of Facility-Community Linkages

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**Total Session Time:**      35 minutes



### **Trainer Instructions**

Slides 1-5

**Note:** If time allows, trainers may want to invite guest speakers to attend this module. Possible guest speakers might include support group leaders, youth group leaders, home-based care organisation leaders or experienced staff from income-generation, vocational support, food support, or legal aid organisations. Be sure to prepare the guest speakers in advance and ask each to spend about 5 minutes discussing their programme and how they foster linkages with other agencies. Invited guests can also join the small groups for these sessions.

**Step 1:**      Begin by reviewing the Module 11 learning objectives and the session objectives, listed below.

**Step 2:**      Ask participants if there are any questions before moving on.

### **Session Objectives**

**After completing this session, participants will be able to:**

- Discuss common challenges and strategies to creating strong facility-community linkages in support of ALHIV and their caregivers
- Describe community-based support services that ALHIV and their caregivers may need



### **Trainer Instructions**

Slides 6-11

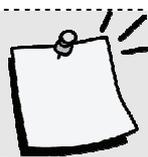
**Step 3:**      In order to provide a continuum of care and support to ALHIV and their caregivers/families, healthcare workers must actively help them get the services they need — at the health facility, in the community, and at home. Ask participants to brainstorm some of the common challenges or barriers to these community-facility linkages, using these questions as a guide:

- *What are some of the challenges to having good facility-community linkages?*

- *What are some of the specific ways we can improve facility-community linkages for ALHIV and their caregivers?*

**Step 4:** Next, ask participants to brainstorm and discuss the ways in which healthcare workers and multidisciplinary teams can improve linkages between the facility and the communities they serve, given the challenges and current resources. ***Emphasize the importance of simply reaching out (by phone, e-mail or in person) to colleagues in other organisations who provide services to young people. The key to establishing linkages is simply getting away from the office or clinic and meeting colleagues who work for peer organisations!***

Record responses on flip chart. Fill in, as needed, from the information below.



### **Make These Points**

- Linkages to community resources and support are important to help ALHIV and their caregivers get access to services and support they need, across the continuum of HIV care.
- There are community-based services available for PLHIV, including ALHIV, in most places, but often groups and organisations do not know about each other or are unaware how they can work together. Without this collaboration, healthcare workers are handicapped in their ability to refer clients and their families to the community-based organisations that can assist them.
- Some key challenges to facility-community linkages are a lack of awareness of community-based services, lack of awareness of the special needs of adolescents, scarcity of community services specifically for ALHIV, and lack of coordination of services.
- There are many ways to strengthen facility-community linkages, such as informal and formal meetings with community and youth group leaders; orienting community organisations and staff/volunteers working with youth on the needs of ALHIV; and developing a strong two-way referral system between the health facility and community organisations working with PLHIV, ALHIV, and youth in general.

## **Improving Facility-Community Linkages**

### **Challenges to facility-community linkages**

Some key challenges to facility-community linkages include the following:

- Healthcare workers may not be aware of community-based services or there is no mechanism to exchange information or formalise 2-way referrals.
- Community organisations and leaders may not be aware of adolescent HIV services at the health facility or lack training in this area.
- Schools may not be familiar with ALHIV and the needs of youth who are most-at-risk, like orphans and other vulnerable children.
- Community organisations and leaders do not trust facility-based services or may prefer traditional medicine or healing.
- There may not be any community services specifically for ALHIV.
- Community members, including adolescents, may not understand the need for HIV-related services at the health facility.
- Adolescents may get treated poorly when they go to the health facility, and this information spreads through the community.
- Service delivery may be fragmented, uncoordinated, and/or not youth-friendly.
- It may cost a lot of money to get from the community to the health facility (transportation costs).

### **Strategies to address barriers**

Below are strategies to improve facility-community linkages and to develop a more coordinated and collaborative approach to ALHIV service delivery.

- Learn what community organisations and services are available in the areas where adolescent clients live (and go to school or work). Make an appointment and go to these organisations. Invite them to visit the health facility for an informal meeting or a formal tour and “open house”. Meet with the staff to find out what services they offer, discuss the services offered at your facility, and set up formal or informal “2-way” referral systems. This means that the health facility can refer adolescents to the community organisation and the community organisation can refer adolescent clients to the health facility.
- Facilitate regular (for example, monthly or quarterly) meetings between health facility managers and staff and the staff of community-based youth groups, youth Peer Educators, school heads and teachers, PLHIV associations, community healthcare workers, and others to share insights and information about the special needs of ALHIV, the services available at health facilities and in the community, and how to facilitate interagency linkages and referrals.
- Meet with community leaders to talk with them about ALHIV and HIV care and treatment services and why they are important. Also try to clarify common myths about HIV, ALHIV, and ARVs.
- Participate in community meetings and community gatherings to discuss HIV, ALHIV, and care and treatment.
- Train/orient existing community-based Peer Educators and community healthcare workers to identify adolescents and refer them for HIV testing and care and treatment. They can also be trained to provide

basic adherence and psychosocial support to ALHIV and their caregivers and to follow up with clients who have missed appointments.

- Start support groups for adolescents of different ages/stages at the health facility or in the community. Invite community healthcare workers to the support group meetings to provide guidance and information. See Module 5 for more information on setting up and leading support groups.
- Involve young community members openly living with HIV to strengthen facility-community linkages, such as by starting an adolescent peer education programme (see Session 11.3).



### **Trainer Instructions**

Slides 12-14

#### **Step 5:**

Ask participants to brainstorm common support needs of ALHIV that can be provided in the community or in the home. Record responses on flip chart. Ask participants to identify from the list the 5 most important community support needs. Circle these on the flip chart.

In reference to the 5 most important needs, ask participants the following questions to facilitate discussion; record key points on flip chart.

- *Why is this type of community or home-based support important for ALHIV?*
- *What specific organisations provide this type of support in your community? What have been your challenges and successes linking with these groups?*
- *How are these organisations currently linked to the health facility?*

#### **Step 6:**

(optional) Ask the adolescent co-trainer to describe some of the community services for ALHIV.

- *In your experience, what type of community-based support is important to ALHIV and their families?*
- *Which organisations provide this support in your community?*
- *What are your experiences with this type of support?*
- *What are your experiences with community referrals and how do you think we can strengthen referrals between the health facility and community organisations to meet the needs of ALHIV and their families?*



### **Make These Points**

- No one person or organisation can provide all of the services and support ALHIV need. It is important to have a formal 2-way referral process between facility- and community-based services and to follow up on all referrals made.
- Some common needs of ALHIV and their families at the community and home levels include support groups, psychosocial support, adherence support, home-based care and support, poverty reduction and income-generating activities, educational support including formal and vocational education, job placement, help for OVC-headed households, nutrition support, and food relief.

## Community Support Needs of ALHIV

Examples of common support needs of ALHIV, their caregivers, and families include:

- ALHIV support groups (including support groups for different ages/stages of adolescents) and associations
- Disclosure support (both for caregivers and for adolescents)
- Nutritional and food support
- Spiritual guidance and support
- Transportation to get to the clinic
- Education and counselling for caregivers and family members
- Social grants
- Grants to purchase supplies, such as soap, school supplies, school uniforms, condoms, etc.
- Support for child-headed households, orphans and vulnerable children
- Access to formal and non-formal education, including vocational training (for example, school/tuition fees) and life skills training
- Job preparation and placement
- Income-generating activities and savings and loan programmes
- Home-based care
- Home-based adherence support
- Home-based infant feeding support
- Legal advice and support
- Others...

### Continuum of care

=

### multi-agency

Remember, no single person or organisation can provide all of the services and support ALHIV and their families need. We must work together to provide a continuum of ongoing care and support in the health facility, in the community, and at home.



### Trainer Instructions

**Step 7:** Allow 5 minutes for questions and answers on this session.

## Session 11.2      **Creating a Community Resource Directory**

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**Total Session Time:**      75 minutes (1 hour, 15 minutes)



### **Trainer Instructions** Slides 15-16

- Step 1:**      Begin by reviewing the session objective listed below.
- Step 2:**      Ask participants if there are any questions before moving on.

### **Session Objective**

**After completing this session, participants will be able to:**

- Create a community resource directory for adolescent clients and caregivers.



### **Trainer Instructions** Slides 17-19

- Step 3:**      Introduce the session by stating that we have discussed the comprehensive community support needs of ALHIV and their caregivers and families, and now we will talk about how we as healthcare workers will link them to available community- and home-based services.
- Lead a discussion on the importance of setting up and using 2-way referral systems, by asking:
- *What are the informal and formal referral processes used to link clients with support services (including forms used) at your clinic and in the surrounding community?*
  - *What are the specific steps in making a referral from the health facility to a community organisation? From a community organisation to the health facility?*
  - *What is done to follow up the referral, to ensure that the client received the services to which he or she was referred?*
- If possible, provide specific examples of facility-community referral forms and explain how they are used.
- Step 4:**      Explain that healthcare workers can also help improve facility-community linkages by creating and using a community

resource directory. Ask if any participants use any type of community referral/resource directory at their clinic now; allow time to share experiences.



### **Make These Points**

- Healthcare workers should stay up-to-date on which services are available for ALHIV and their caregivers/families and maintain a directory of these services to facilitate making referrals. Such directories should be shared with community organisations so that they, too, have current lists of the community- and health facility-based services for adolescents.
- In some places, resource directories for youth and/or PLHIV may already exist, so check in with your local PLHIV associations, district HIV teams, district health committees, or other coordinating organisations.
- Healthcare workers and teams can work with youth and community organisations to keep their community resource directories up-to-date. They may also want to use the directory to create a community resource map for ALHIV and their families.

## **Creating a Community Resource Directory**

In order to provide effective referrals, healthcare workers need to be up-to-date on the community services available to young people and ALHIV.

- A good way of knowing where to refer clients is for each health facility to develop and regularly update a community resource directory (see “Appendix 11A: Community Resource Directory Template”). This makes it easier to refer clients to needed services.
- Each clinic should have an up-to-date community resource directory and formal two-way referral systems to and from these organisations and services. The resource directory should include day/times services are offered, fees, documentation required at initial visit, address, phone number, contact person, etc. The community resource directories should be posted in the clinic waiting room and available in all of the examination and counselling rooms for easy reference.
- Healthcare workers can also work together with youth (for example, Peer Educators) to map available resources for ALHIV and families in the community and post this map in the clinic and/or give photocopies of the map to clients.
- Resource directories need to be updated regularly to keep up with personnel changes and changes in addresses phone number or other changes. It is a good idea for one person to be responsible for keeping up to date with these changes as they occur.



### Trainer Instructions

Slides 20-22

**Step 5:** Lead participants through Exercise 1, which gives them an opportunity to develop a Community Resource Directory for adolescent clients and families at their health facility.

### Exercise 1: Creating a Community Resource Directory: Small group work and large group discussion

<b>Purpose</b>	<ul style="list-style-type: none"><li>To provide an opportunity for participants to brainstorm and create their own resource directory</li></ul>
<b>Duration</b>	60 minutes
<b>Advance Preparation</b>	<ul style="list-style-type: none"><li>Contact any district HIV committees and local NGOs, and request copies of any existing community HIV support resource directories. Try to get enough copies for each participant.</li><li>Invited guests from community organisations can join the small groups for this discussion.</li></ul>
<b>Introduction</b>	In this exercise, healthcare workers from the same facilities will work together to begin to develop a Community Resource Directory for adolescent clients and their family members. Tell participants that one of the important ways healthcare workers can help improve facility-community linkages for clients and their families is by creating, maintaining and using a community resource directory. Resource directories facilitate sharing of information about community resources and how our clients can access these resources.
<b>Activities</b>	<p><b>Small Group Work</b></p> <ol style="list-style-type: none"><li>Break participants into small groups. Participants working at the same health facility should be grouped together.</li><li>If available, hand out any existing community resource directories collected before the training.</li><li>Refer participants to “Appendix 11A: Community Resource Directory Template”.</li><li>Ask each small group to take about 40 minutes to brainstorm the community support services available to ALHIV and families affected by HIV in their facility’s catchment area. Each small group should begin to fill in “Appendix 11A: Community Resource Directory Template”, thinking specifically about the availability of the following services:<ul style="list-style-type: none"><li>ALHIV support groups</li><li>Nutritional and food support, such as community food banks</li><li>Home-based care and adherence support</li></ul></li></ol>

	<ul style="list-style-type: none"> <li>• Education and counselling for caregivers and family members</li> <li>• Social grants</li> <li>• Supplies, such as soap, school supplies, school uniforms, etc.</li> <li>• Support for child-headed households and orphans and vulnerable children</li> <li>• Education and life skills programmes</li> <li>• Job preparation and placement programmes</li> <li>• Spiritual guidance and support</li> <li>• Condom suppliers</li> <li>• Income-generating programmes</li> <li>• Legal advice and support</li> <li>• Others...</li> </ul> <p>For each service, participants should also discuss the following questions in their small groups:</p> <ul style="list-style-type: none"> <li>• <i>What is being done now to link clients with these groups and organisations?</i></li> <li>• <i>What could be done to improve referral linkages with the groups and organisations listed in the directory?</i></li> </ul> <p><b>Large Group Discussion</b></p> <p>5. After about 40 minutes, bring the large group back together. If there is sufficient time, give each of the small groups about 5 minutes to present highlights of their discussion and Community Resource Directory.</p> <p>6. Ask the following questions to facilitate discussion within the large group:</p> <ul style="list-style-type: none"> <li>• <i>What are the next steps you will take to complete your Community Resource Directory?</i></li> <li>• <i>How will you use the Directory in your clinic?</i></li> <li>• <i>How will you keep the Directory updated?</i></li> </ul> <p>7. (optional) Ask the adolescent co-trainer to participate in one of the small groups, providing input and perspective about available community-based support services for ALHIV and youth.</p>
<b>Debriefing</b>	<ul style="list-style-type: none"> <li>• To ensure good facility-community referrals, it is essential for healthcare workers to develop, maintain and use an up-to-date community resource directory.</li> <li>• As a next step, healthcare workers can go back to their health facilities and work with other members of their team and community organisations to complete the matrix.</li> <li>• It is important to keep the directory up-to-date. Someone can be assigned to update the directory every 6 months or so. It is best if Peer Educators and other youth can also be involved in this process.</li> </ul>



### **Trainer Instructions**

**Step 6:** Allow 5 minutes for questions and answers on this session.

## Session 11.3 Adolescent Participation and Peer Education Programmes



**Total Session Time:** 55 minutes



### Trainer Instructions

Slides 23-24

- Step 1:** Begin by reviewing the session objectives listed below.
- Step 2:** Ask participants if there are any questions before moving on.

### Session Objectives

**After completing this session, participants will be able to:**

- Describe the rationale for meaningful adolescent involvement and effective strategies to involve adolescents in service delivery.
- Understand the key components to implementing a successful adolescent Peer Educator programme.



### Trainer Instructions

Slides 25-36

- Step 3:** Remind participants about the importance of ensuring that services are accessible and youth-friendly throughout the training. Revisit the benefits and importance of youth involvement in programme design, programme evaluation, and service delivery.

Based on these discussions and their experiences, ask participants to brainstorm the advantages of meaningful adolescent involvement in adolescent HIV care and treatment programmes. Ask the following questions to guide the discussion:

- *Why do you think it is important to involve ALHIV in programme design, evaluation, and implementation?*
- *What, if any, youth involvement do you have in your current programme?*
- *What kinds of youth participation do you think you could start or expand in your health facility?*

Provide an overview of the CAB (as a community, client or

consumer advisory board) and how it might work in an adolescent care and treatment setting. Ask:

- *What is a “CAB” (client/consumer/community advisory board)?*
- *Is anyone familiar with CABs? Do you have a CAB at your clinic?*
- *If so, how do they work? If not, do you think they would work in your setting?*
- *Do you think it might be possible to recruit adolescents and their caregivers to function as adolescent HIV CAB members? If not, why not? If so, what challenges would you foresee with this?*

**Step 4:** Discuss common mistakes made when involving people living with HIV in programme planning and implementation. One common error is “tokenism”; that is, the involvement of people in a way that does not contribute to the organisations goals and objectives.

- *Have you ever seen youth involved in a way that was not productive to the organisation? Is it possible to make mistakes when involving youth?*
- *If so, what mistakes have you seen or could you imagine happening?*

Review content on “tokenism” and section entitled “Ensure Expectations are Appropriate”.

**Step 5:** (optional) Ask the adolescent co-trainer to offer their input and opinion by asking:

- *In your experience, what role can young people play in adolescent HIV care and treatment programme planning, evaluation, and service delivery to their peers?*
- *What should mistakes would you ask healthcare workers avoid when engaging youth?*



### **Make These Points**

- PLHIV participation in all aspects of HIV programmes is critical to ensure that programmes are designed and implemented to meet client needs.
- It is important to ensure youth participation from the beginning of the programme (if possible) because it helps them to have a sense of ownership of the project and can help guarantee better commitment to and participation in the project and the services provided.
- CABs are autonomous bodies that include clients and their caregivers

as members. CABs are officially recognised by the programme they represent; their role is to advise the clinic on quality of services, gaps in care and make recommendations to improve service provision.

- Young people, such as Peer Educators, can play important roles in direct service delivery with their peers, as well as planning, monitoring, evaluation and quality assurance activities at the facility.
- As ALHIV and service recipients themselves, Adolescent Peer Educators can give meaningful feedback to healthcare programmes, offering insights into the best ways retain young people in care and support their adherence to ART.
- Forming real and meaningful adolescent-adult partnerships — in which adolescents are viewed as equal team members — is vital to the success of adolescent HIV services.
- The role of an adolescent in programme delivery needs to match his or her developmental capacity and responsibilities always appropriate for age and ability. It is not appropriate to delegate responsibility to Peer Educators (such as counselling responsibilities) for which they have not been trained.

## **Adolescent Involvement<sup>1</sup>**

The meaningful involvement of PLHIV and affected communities makes a powerful contribution to the HIV response by supporting people to draw on their own experiences to increase the effectiveness and appropriateness of services. PLHIV participation in all aspects of HIV programmes is critical to ensure that services are designed and implemented to meet client needs.

Effective and meaningful adolescent involvement in service delivery requires commitment from every member of the multidisciplinary care team.

Two important mechanisms to formally involve adolescent clients in service planning, implementation and evaluation is through the engagement of ALHIV as Peer Educators and the establishment of ALHIV consumer (or community or client) advisory boards (CAB). Both are discussed below.

### **Adolescent Peer Educators**

Adolescent Peer Educators can complement the work of healthcare providers and play an important role in improving adherence and service quality. Peer education offers many benefits to HIV care and treatment programmes, among them:

#### **A safe environment:**

- People trust others in similar situations, so ALHIV feel safer discussing their personal circumstances with someone who shares and relates to their situation and is also an adolescent.

**Improved adherence:**

- Peer Educators can support clients' adherence because they may have a deeper understanding of the challenges faced by other adolescents and the range of potential solutions to those challenges.
- Youth involvement and youth providers make HIV care and treatment services more attractive to adolescents, and likely improve their adherence to and retention in care.

**Improved linkages:**

- Peer Educators can draw on their own knowledge and experiences to help other ALHIV navigate health facilities and strengthen linkages between the clinic and community services.

**Positive living:**

- Building on their own experiences, Peer Educators can serve as role models to encourage positive living and positive prevention.
- Programmes can empower and create positive changes in the lives of the Peer Educators themselves, help to decrease stigma and discrimination against ALHIV in the community, and encourage other adolescents in the community to access HIV services.

**Improved service quality:**

- ALHIV Peer Educators can help programmes become more youth friendly. They can also help identify and address programme barriers in reaching young people.
- Adolescent Peer Educators are in a unique position to contribute to quality assurance activities, based on their own experiences as clients in the programme and by soliciting feedback from their peers.
- Peer Educators can make services more accessible to youth, by helping to plan and facilitate peer support groups and activities, using art, drama, music, sports, and other youth-friendly activities.

**Community participation and advocacy:**

- Peer Educators can play a role in community mobilisation, decreasing stigma, serving as positive role models, and increasing support for ALHIV.

**Job opportunities:**

- The training and work experience that comes with the Peer Educators job will prepare these adolescents for future job opportunities in the formal economic sector.

**Increased access to services:**

- When young people, such as adolescent Peer Educators, also conduct outreach and advocacy work in their communities, more adolescents are reached with information about clinical services.

- Adolescent Peer Educators can also play a role in identifying and reaching most at-risk adolescents in their communities.

### **Clients served have a closer connection to young providers:**

- Young people are a vital source of information about youth needs.
- Programmes that utilise youth staff tend to address young clients' needs and concerns more sensitively and accurately.
- Peers may hear of client challenges or successes that don't come to the attention of other team members.
- Also, young people often speak the "same language" and Peer Educators can help explain things in terms and language that their peers will understand (instead of, for example, formal or clinical adult language and ways of explaining things).

### **CABs**

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Some healthcare programmes may be interested in establishing a formal mechanism to facilitate feedback from clients through the establishment of a CAB. CABs are autonomous bodies that advise the clinic on quality of services, gaps in care and make recommendations to improve service provision. CABs:

- Include 5–20 members, 7–9 is typical, most or all of whom are clients or caregivers. Members should be able to represent a wide range of the clients served by the clinic.
- Typically meet every other week at first, and then once established, monthly.
- Have a direct line of communication with clinic management. Typically a clinical manager would attend every meeting.
- Are guided by a set of by-laws developed by members and approved by the clinic they advise.

### **Avoid Tokenism**

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Adolescents should be recognised, integrated and supported as the vital human resource that they are. Tokenism is NOT partnership or meaningful involvement and participation. Examples of tokenism include:

- Having youth present but with no clear role, training, support, or supervision. Both CAB members and adolescent Peer Educators need training before they can fully contribute in their new roles. They also need ongoing support and supervision to continue to develop skill and capacity.
- Asking youth their opinions, but not taking them seriously or incorporating them into programme decisions or planning
- Assigning to youth tasks that adults do not want to do, such as filing or cleaning

## Ensure Expectations are Appropriate

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Remember: Health facilities should always use a developmental perspective when involving adolescents in programme delivery:

- Keep expectations and assigned responsibilities and tasks realistic; expectations should always match an adolescent's developmental capacity and responsibilities should always be appropriate for their age and ability. So, for example, an adolescent Peer Educator should not be expected to provide professional level counselling or mental health screening and management to other clients.
- Provide follow-up training and ongoing mentoring and supervision. If Peer Educators are not well trained it will compromise the quality and effectiveness of their work. Peer Educators also need ongoing support, mentoring and supervision. They need an experienced supervisor to:
  - Observe their work, frequently at first and then regularly thereafter (for example, weekly progressing to monthly) and provide constructive feedback afterwards. The supervisor should observe both one-to-one interactions and interactions within the support group setting.
  - Lend a listening ear. As an ALHIV, it can be difficult to separate yourself and your issues from those of your clients. The death of a client can be a particularly difficult time, during which Peer Educators may require much support.
  - Answer questions.
  - Not “look over their shoulders”, as this can undermine self-confidence and client confidence in their work.
- It is important to make the boundaries with adolescent Peer Educators and CAB members very clear and to enforce them in a transparent way. Make sure that the programme has stated policies and rules for addressing what is appropriate and inappropriate behaviour and make sure that Peer Educators are appropriately supervised and supported to adhere to these policies.



### Trainer Instructions

Slides 37-42

- Step 6:** Introduce this section by noting that we have spoken extensively about the value of and need for peer support in educating and assisting ALHIV and their caregivers. If not done already, ask if anyone has an adolescent peer education programme in his or her facility currently and allow time to share experiences.
- Step 7:** Ask participants:
- *Based on your experience, what are the roles and responsibilities of Peer Educators within the clinic setting?*
  - *What are the key steps to implement a Peer Educator*

*programme?*

Record responses on flip chart. Review the 10 key steps to set up an adolescent peer education programme. Then ask:

- *What should be the selection criteria for Peer Educators?*

Review key points about Peer Educator job descriptions (including what Peer Educators should NOT be asked to do) and selection criteria.

**Step 8:** (optional) Ask the adolescent co-trainer to offer his or her input and opinion:

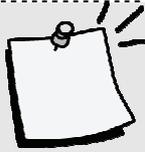
- *Describe some of your experiences with peer education programmes and peer support meetings. How do they contribute or add value to service delivery for ALHIV?*

**Step 9:** Remind participants that one of the most important contributions of Peer Educators is their participation in the design and delivery of peer support groups for ALHIV and their caregivers. For example, they can assist the group facilitator with planning and leading support group meetings and also help identify youth-friendly activities and discussion topics relevant for ALHIV. Additional information about planning and starting a peer support group in your facility is in Module 5.

**Step 10:** Next ask participants to brainstorm about the feasibility and “next steps” for implementing an adolescent peer education programme in their health facility. Ask the following questions:

- *If you already have an adolescent peer education programme in your facility, how could it be improved?*
- *If not, do you think it's feasible to start an adolescent peer education programme in your facility? What would be the next steps?*
- *What do/will the Peer Educators do at your facility? What are your expectations for their roles and responsibilities?*
- *What would you NOT expect them to do, compared to adult Peer Educators or adult lay providers? How would these expectations be managed and enforced by supervisors?*
- *How will they be selected? How will they be trained? How will they be supervised?*

Remind participants that managing a peer education programme is a big responsibility that requires careful planning and oversight. Tell participants that they will have more time to discuss these steps during the Action Planning Session in Module 15.



### **Make These Points**

- Peer education can be a powerful approach to improving the youth-friendliness and quality of ALHIV care and treatment services.
- Careful planning, clear objectives, regular supervision, and good communication are essential for successful implementation of a peer education programme.
- Implementation of a peer education programme involves 10 main steps:
  1. Conduct a participatory situational analysis and needs assessment.
  2. Engage stakeholders in participatory programme design.
  3. Define programme indicators, set targets, and develop tools.
  4. Develop a detailed budget and workplan.
  5. Recruit Peer Educators, based on selection criteria.
  6. Adapt or develop a Peer Educator training curriculum.
  7. Train Peer Educators.
  8. Engage health facility teams to rollout peer education activities.
  9. Provide ongoing support, supervision, and mentoring to Peer Educators.
  10. Continuously monitor, evaluate, and adjust the programme.

## **Key Steps to Implementing a Facility-based Adolescent Peer Education Programme**

Before implementing a peer education programme, it is important to consider how Peer Educators will function within the existing programme framework — that is, how Peer Educators will assist other adolescent clients and how they will become part of the multidisciplinary team as a whole. Neglecting to do so can result in unclear job descriptions, mismatched expectations, poor peer performance, and ultimately, compromised client service.

### **Key steps to implement a programme<sup>2</sup>**

There are 10 key steps for implementing effective Peer Educator programmes are as follows:

1. Conduct a participatory situational analysis and needs assessment: Ask colleagues, adolescent clients, and caregivers how youth are involved at the moment, how they can be involved, and how they are involved in planning, implementing and evaluating services at other organisations.
2. Engage stakeholders in participatory programme design: Ask adolescents and their caregivers how they would like the peer involvement project structured. What should the Peer Educators do? How should they be trained and managed?
3. Define programme indicators, set targets, and develop tools: Indicators and targets might be, for example: “To train 12 Peer Educators by April

- 1, 2012.” “To engage 6 Peer Educators by May 1, 2012. Tools might include supervisory tools, job descriptions, personal criteria, etc.
4. Develop a detailed budget and workplan: This is the budget and workplan that cover the cost and activities involved in recruiting, training and engaging Peer Educators.
  5. Recruit Peer Educators, based on selection criteria
  6. Adapt or develop a Peer Educator training curriculum
  7. Train Peer Educators
  8. Engage health facility teams to rollout peer education activities
  9. Provide ongoing support, supervision, and mentoring to Peer Educators
  10. Continuously monitor, evaluate, and adjust the programme

A sample job description for Adolescent Peer Educators is included as “Appendix 11B: Template for Adolescent Peer Educator Job Description”.

### **Qualifications of Peer Educators**

Some suggested qualifications for Peer Educators are as follows:

- Older adolescent
- Living positively with HIV
- Adherent to care and medications
- Open-minded and non-judgemental attitude (for example, respectful and tolerant of different perspectives, cultural backgrounds, and lifestyles)
- Basic literacy and numeracy skills
- Good interpersonal and oral communication skills
- Commitment to working with other ALHIV
- Demonstrates self-confidence
- Ability to be self-disciplined and work independently, as well as within a team
- Availability to work at clinic (which does not conflict with school or work attendance)
- Represent age, ethnicity, socio-economic status, gender, language preference/abilities, and other characteristics of adolescent clients at the clinic
- Other qualifications identified by the health facility and as suggested by young people

For additional information on setting up and managing peer education programmes and on training adolescent peer educators see “Appendix 11C: Resources for Peer Educator Programmes and CABs”.



#### **Trainer Instructions**

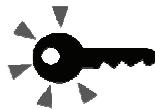
**Step 11:** Allow 5 minutes for questions and answers on this session.



### **Trainer Instructions**

Slides 43-45

- Step 12:** Ask participants what they think the key points of the module are. What information will they take away from this module?
- Step 13:** Summarise the key points of the module using participant feedback and the content below.
- Step 14:** Ask if there are any questions or clarifications.



### **Module 11: Key Points**

- Linkages to community resources and support are important to help ALHIV and their caregivers get the services and support they need, across the continuum of HIV care.
- There are many ways to strengthen facility-community linkages, such as informal and formal meetings with community and youth group leaders; orienting community organisations and staff/volunteers working with youth on the needs of ALHIV; and developing a strong two-way referral system between the health facility and community organisations working with PLHIV, ALHIV, and youth in general.
- Healthcare workers should stay up-to-date on which services are available for ALHIV and their caregivers/families and maintain a directory of these services to facilitate making referrals. Such directories should be shared with community organisations so that they, too, have current lists of the community- and health facility-based services for adolescents.
- PLHIV participation in all aspects of HIV programmes is critical to ensure that programmes are designed and implemented to meet client needs. Young people can play important roles in direct service delivery with their peers, as well as planning, monitoring, evaluation and quality assurance activities at the facility. Two important ways to include adolescents are through CABs and Peer Educator programmes.
- As ALHIV and service recipients themselves, Adolescent Peer Educators can give meaningful feedback to healthcare programmes, offering insights into the best ways retain young people in care and support their adherence to ART.
- Peer education can be a powerful approach to improving the youth-friendliness and quality of ALHIV care and treatment services. But peer education programmes require careful planning, clear objectives, regular supervision, and good communication.

# Appendix 11A: Community Resource Directory Template

DISTRICT NAME: \_\_\_\_\_ FACILITY NAME: \_\_\_\_\_ DATE: \_\_\_\_\_

NAME OF ORGANISATION	SERVICES PROVIDED FOR YOUTH/FAMILIES	GEOGRAPHIC AREAS COVERED	CONTACT PERSON	PHONE NUMBER AND ADDRESS	OTHER*
1.					
2.					
3.					
4.					
5.					
6.					
7.					

NAME OF ORGANISATION	SERVICES PROVIDED FOR YOUTH/FAMILIES	GEORGAPHIC AREAS COVERED	CONTACT PERSON	PHONE NUMBER AND ADDRESS	OTHER*
8.					
9.					
10.					
11.					
12.					
13.					
* "Other" might include, for example, hours of opening, fees, documentation needed at initial visit, information about how to get there (transportation, bus line, directions if difficult to find), etc.					

# Appendix 11B: Template for Adolescent Peer Educator Job Description

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## **Job description:**

### **Adolescent Peer Educators are expected to:**

- Participate as an active member of the multidisciplinary care team in the clinic, including attending meetings and trainings, if required
- Openly disclose their HIV-status to clients
- Help conduct/co-facilitate support groups and other psychosocial support activities for youth living with HIV (YLHIV)
- Conduct peer education sessions with YLHIV and provide support on the following topics:
  - Basic information about HIV and HIV care and treatment
  - Adherence to HIV care and treatment
  - Disclosure
  - Basic emotional and psychosocial support
  - Positive living and positive prevention
  - Safer sex
  - Others, as decided by the programme
- Help YLHIV with referrals within the health facility
- Help link YLHIV with needed community support services
- Be positive living and adherence role models to other YLHIV
- Act as a link between adolescent clients and the multidisciplinary care team
- Keep basic records and compile monthly reports

### **Expectations and time requirements for Adolescent Peer Educators (fill in/adapt as needed):**

- Once selected, Adolescent Peer Educators will be expected to serve at least 1 year in their position.
- Adolescent Peer Educators are expected to attend and participate in the initial 10 day basic adolescent peer education training
- Adolescent Peer Educators will be expected to be present and work at the clinic at least 2–3 days per week.
- Adolescent Peer Educators may be expected to attend meetings or refresher trainings on weekends or during holidays, as needed. Estimated to be (fill in) days per month/year.

### **Supervision and reporting lines:**

Adolescent Peer Educators will report to, and be supervised by, (fill in).

### **Incentives:**

Adolescent Peer Educators are volunteers, but will receive the following incentives, supplies, and stipends (fill in).

## **Appendix 11C: Resources for Peer Educator Programmes and CABs**

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### **FHI Youth Peer Education Toolkit:**

**<http://www.fhi.org/en/Youth/YouthNet/Publications/peeredtoolkit/index.htm>**

The Youth Peer Education Toolkit is a group of resources designed to help programme managers and master trainers of Peer Educators. Collectively, these tools should help develop and maintain more effective peer education programmes. The 5 parts of the toolkit are based on research and evidence from the field as well as local examples and experiences. They are designed to be adapted locally as needed. The toolkit resulted from a collaboration between the United Nations Population Fund (UNFPA) and Family Health International. It was produced for the Youth Peer Education Network (Y-PEER), a project coordinated by UNFPA.

The 5 parts of the toolkit are as follows:

1. Training of Trainers Manual
2. Standards for Peer Education Programmes
3. Theatre-Based Techniques for Youth Peer Education
4. Performance Improvement
5. Assessing the Quality of Youth Peer Education Programmes

### **ICAP, Comprehensive Peer Educator Training Curriculum,**

**<http://cumc.columbia.edu/dept/icap/resources/peresources/PE.html>**

To share lessons learned, experiences and materials more widely, ICAP developed, and has recently updated per the new WHO guidelines, generic Peer Educator materials, which can be adapted by organisations and implementing partners wishing to start or scale-up peer education programmes.

Training content areas were selected to prepare Peer Educators for integration into the multidisciplinary HIV care team and provide added support in key areas of PMTCT and HIV care and treatment service delivery. The curriculum contains 15 basic and 4 advanced Modules. Both Manuals can easily be adapted to specific country and programme contexts.

The training curriculum consists of 3 components:

1. Trainer Manual, which is highly participatory, easy to follow and contains step-by-step instructions for facilitators.
2. Participant Manual, which includes key information, as well as illustrations to engage participants and improve learning. The Participant Manual can also be used as a reference for Peer Educators after the training.
3. Implementation Manual, which will be helpful to Ministries of Health, PLHIV Associations or NGOs initiating or expanding facility-based Peer Educator programmes. It provides practical advice on planning, managing and monitoring Peer Educator programmes. The Appendices of the Manual include a number of generic tools that can be adapted.

**ICAP, Positive Voices, Positive Choices: A Comprehensive Training Curriculum for Adolescent Peer Educators (coming soon in May 2011)**  
**<http://www.columbia-icap.org/resources/peresources/index.html>**

A generic curriculum to train adolescent Peer Educators, developed by ICAP, which will be available on the ICAP website in mid-2011. This easy-to-use, youth-friendly curriculum (Trainer Manual and illustrated Participant Manual) can be adapted to a range of country, program, and organizational settings wishing to start, scale-up or improve the involvement of ALHIV as Peer Educators.

**IMPAACT Community Advisory Board (ICAB) Training Curriculum: Trainer Manual**

**<https://impaactgroup.org/icab-trainer-manual>**

Although the ICAB training curriculum is designed to provide training and support to CAB members responsible for advising research and clinical trials, the first module of the curriculum includes content on how to develop a CAB mission statement, identify goals, determine CAB structure, and develop standard operating procedures.

## References and Resources

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<sup>1</sup> Colton, T., Costa, C., Twyman, P., Westra, L., and Abrams, E. 2009. *Planning, Managing and Monitoring Peer Educator Programs: An Implementation Manual, Version 1.0.*, International Center for AIDS Care and Treatment Programs (ICAP).

<sup>2</sup> Colton, T., Costa, C., Twyman, P., Westra, L., and Abrams, E. 2009. *Planning, Managing and Monitoring Peer Educator Programs: An Implementation Manual, Version 1.0.*, International Center for AIDS Care and Treatment Programs (ICAP).



# Module 12 Supporting the Transition to Adult Care



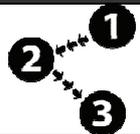
**Total Module Time:** 100 minutes (1 hour, 40 minutes)

## Learning Objectives

**After completing this module, participants will be able to:**

- Understand the key considerations when transitioning from paediatric to adolescent to adult care.
- Prepare adolescents for, and support them in, the transition to adult care.

## Methodologies



- Interactive trainer presentation
- Large group discussion
- Brainstorming

## Materials Needed



- Slide set for Module 12
- Flip chart and markers
- Tape or Bostik
- Participants should have their Participant Manuals. The Participant Manual contains background technical content and information for the exercises.

## References and Resources



- WHO. 2010. *IMAI One-day orientation on Adolescents Living with HIV, Facilitator Guide*, Geneva, WHO Press.
- Jacob, S. and Jearld, S. 2007. *Transitioning Your HIV+ Youth to Healthy Adulthood: A Guide for Health Care Providers*, Transition Consortium, New York.
- Life Skills Subgroup of the AETC Adolescent HIV/AIDS Workgroup. 2006. *Adolescent Transition Workbook*. AIDS Education and Training Center.

## Advance Preparation



- Read through the entire module and ensure that all trainers are prepared and comfortable with the content and methodologies.
- Review the appendices in this module ahead of time and prepare to incorporate them into the discussion.

### **Session 12.1: Key Considerations for Healthcare Transition**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation and large group discussion	20 minutes
Questions and answers	5 minutes
Total Session Time	25 minutes

### **Session 12.2: Preparing and Empowering Adolescent Transition into Adult Care**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation and large group discussion	30 minutes
Exercise 1: Supporting ALHIV in their Transition to Adult Care: Case studies and large group discussion	30 minutes
Questions and answers	5 minutes
Review of key points	10 minutes
Total Session Time	75 minutes

## Session 12.1      Key Considerations for Healthcare Transition

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**Total Session Time:**      25 minutes



### **Trainer Instructions** Slides 1-4

- Step 1:**      Begin by reviewing the Module 12 learning objectives and the session objective, listed below.
- Step 2:**      Ask participants if there are any questions before moving on.

### **Session Objective**

**After completing this session, participants will be able to:**

- Understand the key considerations when transitioning from paediatric to adolescent to adult care.



### **Trainer Instructions** Slides 5-9

- Step 3:**      Explain that in some places, many ALHIV will have attended paediatric clinics, where they may have been getting services since birth or for many years. After a certain age, they may have to transition from the paediatric to the adult ART clinic.
- Encouraging and helping an older ALHIV transition to adult care supports their healthy development and increases their overall ability to advocate for themselves and to adequately manage their own care and treatment.
- Step 4:**      Ask participants the following questions to facilitate discussion, and record key points on the flip chart:
- *What are some challenges ALHIV might face when transitioning to adult care?*
  - *What are some of the challenges that we, as healthcare workers, face when transitioning our adolescent clients into adult care?* (Responses may include: breaking the emotional bonds that we have with our adolescent clients; losing patients, which may have funding implications; fearing a shrinking client base — as PMTCT programmes are better established fewer clients enter adolescent HIV programmes)

in comparison to the numbers that are transitioned out, leading to smaller and smaller programmes.)

- *What fears or concerns do you think ALHIV may have about transitioning to adult care?*
- *What might be some concerns that caregivers of adolescents have about transition to adult care?*
- *What experiences have you (or healthcare workers in adult HIV programmes) had receiving adolescent clients from paediatric programmes?*
- *How can healthcare workers help manage these fears, expectations, and challenges and support adolescents' transition to adult care?*

**Step 5:** (optional) Ask the adolescent co-trainer to describe some the fears, concerns, or expectations that he or she or other adolescents may have or had when transitioning to the adult ART clinic.



### **Make These Points**

- In some places, adolescents will have attended paediatric clinics, where they may have been getting services since birth or for many years. After a certain age, they may have to transition to the adult ART clinic, because the paediatric clinics may not be able to provide care for them after they reach a certain age.
- This care transition can be difficult for many reasons. Adolescents may have concerns about leaving trusted providers and having new providers that do not know them well, getting care in an unfamiliar environment, fear of stigma, concern about quality of care, size of the clinic, being seen by other community members, etc.
- These changes affect healthcare workers and clinic staff, as well as adolescents and their caregivers, since ALHIV have to start taking more responsibility for themselves and their care leading up to and through the transition period.
- Transition to adult care requires helping the adolescent manage and adjust to changes in the organisation of care. Ideally this would entail increased family involvement in the adolescent's care in preparation for transition, and ensuring good client–healthcare worker and client-caregiver communication throughout the process of transition.

## Key Considerations for Transition to Adult Care

There are parallels between the maturation of adolescents into adults and the transition from paediatric to adult HIV programmes. ALHIV may face challenges to transitioning to adult care or learning to independently manage their own care. These challenges affect healthcare workers in paediatric and adult clinics, as well as adolescents and their caregivers. The role of the healthcare worker is to provide ALHIV and their caregivers with adequate support and to help them to increase their capacity to manage their own care and advocate for themselves in the clinical setting.

### Goal of transition

The goal of transition is to ensure the provision of health care that is uninterrupted, coordinated, developmentally and age appropriate, and comprehensive before, during and after the transition.

Some key challenges for ALHIV during the transition process may include:

- **Balancing complicated care:** Adolescents must manage multiple medications and appointments, and must deal with a variety and a range of providers.
- **Leaving a familiar care network:** Adolescent clients may feel a reluctance to leave a familiar care setting and may be fearful and uncertain about how to manage a new clinic setting, new providers, and losing contact with support networks and friends in the clinic.
- **Psychosocial and developmental challenges:** Adolescents are simultaneously coping with the typical changes, feelings and worries of adolescence (which may include relationships, employment, education) and may be struggling with disclosure of their diagnosis to peers and family. Given the number of life changes happening at once, adherence to ART can lose priority. Healthcare workers need to work closely with ALHIV who are about to transition to adult care to ensure that they continue to adhere to their ART regimen and to their care.
- **System challenges:** Adult clinics typically lack specific services for adolescents and a lack of understanding and appreciation of adolescent's needs and issues.

Transition is applicable to every ALHIV as they mature into adulthood. All adolescents require support — within and outside of the clinic setting — to take greater ownership over their health care, behaviour, lives, and adherence to care and treatment.

- Transition to adult care generally occurs in parallel with an adolescent's emotional and physical maturation into adulthood. Effective transition must also allow for the fact that adolescents are undergoing changes that impact much more than their clinical care. Adolescents' psychological maturation may be influenced by how and when they assume responsibility for their care, and vice versa.

- Healthcare workers should help ALHIV set and achieve goals for independence and self-management of care as a way of recognising the young person's increasing maturation, capacity to make choices, and independence.
- Encouragement to develop as much independence as possible, both from their families and healthcare workers, will help bridge the gap to adult services and help adolescents make informed decisions about their own care.
- The overall goal of helping adolescents achieve independent management of their care is a gradual process and should involve the caregivers and family, whenever possible.
- Some caregivers will need assistance to understand their changing roles as the focus moves toward a confidential relationship between the adolescent and the healthcare worker, as opposed to always having a caregiver present at appointments.



#### **Trainer Instructions**

**Step 6:** Allow 5 minutes for questions and answers on this session.

## Session 12.2      Preparing and Empowering Adolescent Transition into Adult Care



**Total Session Time:**      75 minutes (1 hour, 15 minutes)



### **Trainer Instructions**

Slides 10-11

- Step 1:**      Begin by reviewing the session objective listed below.
- Step 2:**      Ask participants if there are any questions before moving on.

### **Session Objective**

**After completing this session, participants will be able to:**

- Prepare adolescents for, and support them in, the transition to adult care.



### **Trainer Instructions**

Slides 12-20

- Step 3:**      In many cases, programmes and facilities do not adequately plan for transition to adult care, which can result in: abrupt transfer to adult services; maintaining adolescents in the paediatric clinic longer than may be appropriate; discontinuation of care; and adherence challenges. Regardless of how a programme manages the transition process, helping all ALHIV achieve greater independence to manage their own care is essential.

Ask participants to reflect on how healthcare workers and clinical programmes can support ALHIV and their caregivers/families in the transition process. Ask the following questions to facilitate discussion and record key points on a flip chart:

- *What do you think is important for older adolescents to know when transitioning to the adult clinic?*
- *What can you specifically suggest to adolescent clients to assist them with the transition process and to assist them with managing their own care?*
- *What youth-friendly activities and/or counselling*

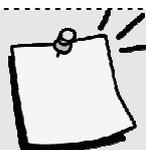
*methods/exercises do you think could help with transition process?*

- *Who should be involved in the transition process?*
- *Who should **lead** the transition process?*

**Step 4:** Refer participants to “Table 12.1: A self-care and transition timeline for ALHIV” and to “Appendix 12A: Transition Checklist for Healthcare Workers”, and briefly review their content. Explain that using these tools can help healthcare workers plan for the transition process, improve ALHIV’s capacity for self-care and self-advocacy, and ease the transition to adult care.

**Step 5:** (optional) Ask the adolescent co-trainer (if willing and comfortable) to reflect on how much he or she has been involved in his or her own care and treatment decisions.

- *What do you have to know to independently manage your own care and treatment?*
- *What have been your experiences as a participant in your own care at the clinic? What are the challenges you have faced managing your own care as a young person?*
- *What were/do you anticipate will be challenges in transitioning to adult care?*



### **Make These Points**

- It is possible for adolescents to have a smooth transition to adult care and receive adolescent-friendly services in the adult clinic, depending on the organisation of the adult clinic, the systems in place to support chronic care, the attitudes of healthcare workers towards adolescents and their understanding of the special needs of ALHIV.
- Adolescents need to be educated, motivated, and supported to take care of themselves, communicate what services they need and what concerns they have. This gives them a better sense of control (i.e. self-efficacy), makes them feel better about their situation, and helps them be more successful in caring for themselves in the long-term.
- Not all ALHIV will be ready to make the transfer to adult care at the same age. Healthcare workers must take into account their cognitive and physical development, their emotional maturity, their support at home and in the community, and their health status.
- Healthcare workers can help to prepare and support older ALHIV who will transition to adult care and keep them linked to youth-specific support groups, adolescent Peer Educators, etc.  
The healthcare worker should begin the transition process early, working as a team with the adolescent client, caregivers, and other members of the multidisciplinary team.

## **Helping ALHIV Prepare for Transition**

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Successful transition involves a client-centred process and a developmental approach; it is not a one-time event. The following principles can help to ensure a smooth transition from paediatric/adolescent to adult care programmes:

- The healthcare worker should begin the process early, working as a team with the adolescent client, caregivers, and other members of the multidisciplinary team.
- The transition process should enhance youth autonomy, cultivate a sense of personal responsibility, facilitate self-reliance and self-efficacy, and boost the adolescent's capacity for self-care and self-advocacy.
- The transfer of care should be individualised and should consider an adolescent's developmental stage.

### **Healthcare workers and Peer Educators can support ALHIV and help them prepare for the transition process by:**

- Reviewing the client's medical history together with the client and encouraging him or her to ask questions about his or her care and medicines and discuss possible changes in the future.
- Ensuring that the adolescent understands his or her diagnosis, needed medications, the importance of adherence to care and medicines, and health precautions including ways to prevent new HIV infections and live positively (see Module 9 for more information about living positively with HIV).
- Promoting linkages to adolescent/peer support groups and to support groups in the adult clinic (for example, programmes can consider having Peer Educators make visits in both adolescent and adult clinics and organise support groups in the paediatric/adolescent clinic for transitioning adolescents).
- Transitioning adolescents to adult care in cohorts or groups, if possible, so adolescents can support one another.
- Organising health talks for transitioning adolescent clients, consider having the talk led by an older adolescent that has successfully transitioned to adult care.
- Encouraging older adolescents to take responsibility in making and keeping appointments and adhering to medicines (for example, ensure the adolescent maintains a calendar of clinic appointments and a medication calendar).
- Identifying and orienting adult providers on the necessity of youth-friendly services — including specific information on the medical and psychosocial needs of ALHIV — through meetings, orientations, and trainings.
- Accompanying the adolescent to the adult clinic for an orientation, to meet the clinic's healthcare workers — including the adult Peer Educators or other lay counsellors — and to discuss specific concerns and questions.

- Transferring medical records to the new clinic and holding case conferences to discuss key issues in the adolescent’s care.
- Involving Peer Educators, social workers, and counsellors when planning for transition to adult care, especially for most-at-risk ALHIV or those with complex needs.
- Using a variety of youth-friendly activities (such as journaling or creating a Transition Workbook in which the adolescent might record information about his or her health, future goals, and sources of support).
- Connecting ALHIV to other community-based services, such as vocational training, social grants, food relief, etc.

**Healthcare workers can help older ALHIV be more involved in their own HIV care and treatment and help prepare them for transition to adult care. They can encourage adolescent clients to:**

- Think ahead about requirements for their care, such as appointments, meetings, adherence requirements (for example, medication refills).
- Ask questions and ask for help, if they need it.
- Learn more about their care and treatment plan.
- Understand which medicines they are taking.
- Get the results of every test and understand the results.
- Join an ALHIV association and a support group.
- Ensure they can follow up on all referrals, if not, ask the right questions to ensure they get the information they need so that they can follow up on referrals.

Healthcare workers can also use “Appendix 12A: Transition Checklist for Healthcare Workers” and Table 12.1, as tools to support ALHIV in the transition process. There are a number of resources available on transition to adult care for healthcare workers and for adolescent clients. Some of these resources are listed in “Appendix 12B: Transition Resources for Healthcare Workers and ALHIV (for Adaptation)” and these can be adapted to any clinical or programme setting.

**Table 12.1: A self-care and transition timeline for ALHIV**

10–12 years old	13–16 years old	16–19 years old
<ul style="list-style-type: none"> <li>• Encourage caregivers to fully disclose to the child</li> <li>• Solicit direct conversation with the adolescent</li> <li>• Increase private meetings and counselling sessions with the adolescent</li> <li>• Begin to explain medications and adherence</li> <li>• Deal with early adherence issues and challenges</li> <li>• Link to support groups</li> </ul>	<ul style="list-style-type: none"> <li>• Assist adolescent with a calendar for appointments and medicines</li> <li>• Ensure adolescent understands diagnosis, needed medications, adherence, health precautions, positive living, and positive prevention</li> </ul>	<ul style="list-style-type: none"> <li>• Enforce responsibility in making and keeping appointments</li> <li>• Provide ALHIV with copies of medical records and any other forms or documents required by the adult clinic</li> <li>• Review medical history with the client</li> <li>• Encourage questions about care plan and treatment regimen and possible changes</li> <li>• Transfer medical records to new provider, highlight key issues</li> <li>• Visit the adult clinic together with the adolescent client</li> </ul>

Adapted from: AETC National Resource Center. 2003. *Practitioner Transition Timeline and Checklist*.



### Trainer Instructions

Slides 21-25

**Step 6:** Lead participants through Exercise 1, which gives an opportunity to discuss how to help ALHIV plan for and transition to adult care.

### Exercise 1: Supporting ALHIV in their Transition to Adult Care: Case studies and large group discussion

<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To discuss particular issues related to transition of care for ALHIV and how healthcare workers can assist to make the transition process smoother</li> </ul>
<b>Duration</b>	30 minutes
<b>Advance Preparation</b>	<ul style="list-style-type: none"> <li>• None required for this exercise</li> </ul>
<b>Introduction</b>	ALHIV need adequate preparation and ongoing support from healthcare workers when transitioning adolescents to the adult clinic. There are many differences between the paediatric, adolescent, and adult care models and adolescents may have many valid concerns about transitioning.

<p><b>Activities</b></p>	<p><b>Large Group Discussion of Case Studies</b></p> <ol style="list-style-type: none"> <li>1. Ask participants to review the case studies and “Appendix 12A: Transition Checklist for Healthcare Workers” in their Participant Manuals.</li> <li>2. Read each case study out loud (or ask for a volunteer to do so). Ask the following questions to facilitate discussion of each case study and record key points on a flip chart. <ul style="list-style-type: none"> <li>• <i>What fears or concerns do you think this client has about transitioning to adult care?</i></li> <li>• <i>What could healthcare workers do to prepare this client for transition to adult care?</i></li> <li>• <i>What types of activities could healthcare workers do with, or suggest to the client, to assist with his or her transition to adult care?</i></li> <li>• <i>What follow up could healthcare workers provide once the adolescent is enrolled in the adult clinic?</i></li> </ul> </li> <li>3. (optional) Encourage participation from the adolescent co-trainer, who can draw on his or her own experience to discuss how the client might be feeling and what healthcare workers can do to ease the transition process.</li> </ol>
<p><b>Debriefing</b></p>	<ul style="list-style-type: none"> <li>• Older ALHIV need support from the entire multidisciplinary care team, and ideally family members, to prepare for transition from the paediatric clinic to the adult clinic.</li> <li>• Healthcare workers can help ALHIV advocate for themselves, be involved and understand their care and treatment, ask questions, and understand referrals and other aspects of their care as they transition to adult the adult clinic.</li> <li>• Healthcare workers can use “Appendix 12A: Transition Checklist for Healthcare Workers”, and adapt some of the other transition resources listed in “Appendix 12B: Transition Resources for Healthcare Workers and ALHIV (for Adaptation)”, to support ALHIV in the transition process.</li> </ul>

**Exercise 1: Supporting ALHIV in their Transition to Adult Care: Case studies and large group discussion**

**Case Study 1:**

Peter is an ALHIV who is 16 years-old. In a few months, he is moving to a new district, where he will need to start getting care and treatment at the adult clinic because there is no paediatric clinic. He is nervous about this change — not knowing the staff and knowing that he will have to deal with a large, crowded clinic. How can you support Peter with this transition?

### **Key points for trainers: Peter**

- **What fears or concerns do you think this client has about transitioning to adult care?**

As noted in the case study, Peter is afraid of the unknown (new clinic staff, new setting with new philosophy of care) and he is afraid of going to a large, crowded healthcare setting. Participants may suggest other fears, which will most certainly be correct as well.

- **What could healthcare workers do to prepare this client for transition to adult care?**

- Starting as soon as possible, you (as the healthcare worker at Peter's current clinic) should help Peter identify exactly what he is afraid of (is he scared of going someplace new? Is he worried that the new doctor will change his medications? Is he worried about getting lost as the building is so big? Is he afraid he'll miss his support group?) and provide counselling to support him to recognise that he can make this change successfully. You should draw on the skills Peter has used in the past to adjust to change (maybe he changed schools last year?).
- Review with Peter his medical history, current medications and key points to communicate to the new clinic.
- Set up linkages with the new clinic. Do you or anyone else at your clinic know any one working at Peter's new clinic? If so, use this personal relationship to identify someone at the new clinic. If not, then just call the new clinic, meet (by phone) the person who can assist him (a nurse, counsellor, Peer Educator or anyone else who can help him feel at home). Set an appointment for Peter's first clinic visit, and find out exactly what Peter needs to bring to that appointment. During the conversation, find out if the new clinic has Peer Educators, case managers, counsellors, support groups or other services that Peter will need.
- Get Peter ready to take on a greater responsibility for his own care. Right now, how does he remember to take his evening or morning ARVs? If his caregiver has to remind him, what can Peter do to wean himself from his caregiver's reminder and start remembering on his own?
- During Peter's last visit to your clinic, make sure he has a copy of his medical record and enough medications to take him to his first appointment at the new clinic.
- See "Appendix 12A: Transition Checklist for Healthcare Workers" for additional activities to support Peter's transition.

- **What types of activities could healthcare workers do with, or suggest to the client, to assist with his or her transition to adult care?**

- If Peter's new district isn't very far, maybe one of the Peer Educators (if possible) can accompany him to his first visit.

- If the new district is not far, maybe Peter can attend an adolescent support group meeting before he relocates, as a way of meeting a few people who could ease his transition.
- Suggest that Peter keep a journal as a way of recoding his feelings, goals and charting his progress. He can also use the same journal as a planner to help him remember his clinic appointments and support group meetings.
- **What follow up could healthcare workers provide once the adolescent is enrolled in the adult clinic?**
  - If Peter has access to a phone, call him the day before his appointment at the new clinic and find out if he is still scared. If he is, offer a listening ear and provide support. The phone call will also function as an appointment reminder.
  - The day after his appointment at the new clinic, call the new clinic to make sure he arrived, respond to any questions they may have about his social or medical history, and discuss if you can assist with any of the next steps agreed with him.

### **Case Study 2:**

Mary is an ALHIV who is 19 years-old. She has been receiving services from the adult clinic for the past year. Recently, Mary has returned to the adolescent clinic to see you. When you ask her about her care and treatment, she tells you that she has stopped taking her ARVs for the last 3 weeks. When you try and discuss this situation with her more in detail, she cries and tells you that she does not like the people at the adult clinic. How would you proceed and support Mary in the transition process?

### **Key points for trainers: Mary**

- **What fears or concerns do you think this client has about transitioning to adult care?**  
Participants will discuss. But the change to the adult clinic was obviously quite dramatic. Assuming Mary adhered to her ARV regimen while attending your clinic, ask her what motivated her at that time? Who reminded her? How are things different now? If she was taking her medications just to please the staff in the adolescent clinic, then try to get her to see this. Let her know that as an adult she now needs to take care of herself for herself, not for anyone else.
- **What could healthcare workers do to prepare this client for transition to adult care?**
  - Keep in mind that Mary was transitioned a year ago. Her case might suggest how the process should be changed. She was obviously unprepared for the transition, was that foreseeable? Did she need more counselling and support to take on more responsibility? Should the transition have been more gradual?

Should it have happened later?

- Help Mary figure out what she is afraid of and dislikes about the adult clinic (Does she dislike how she is treated? Does she miss the comfort and familiarity of the paediatric clinic? Does she dislike the wait time, the number of other patients? Maybe she has to wait in a waiting area with a number of very ill adult patients and this is difficult for her.) Try to figure out whether the key issues are Mary's reluctance to adjust or the adult clinic's unfriendly services.
- Try to address Mary's fears/disadvantages of the adult clinic, one by one. If she feels she's not been treated well, find out who saw her and what happened. Is it possible to reach out to a specific healthcare worker known to be youth-friendly and make an appointment with him or her for Mary's next visit? It is possible that staff in the adult clinic do not have an understanding of the needs of adolescents, if so, can you meet with them and discuss how they can ease not only Mary's transition but also that of other adolescents?
- Ask Mary if she has remained connected to the support group, even if she's transitioning away from the adolescent clinic, she can probably still remain affiliated with the support group here. What would be particularly helpful is a support group for people who are transitioning to adult care that includes adolescents who have transitioned successfully.
- Encourage her to join a young person's support group affiliated with the adult clinic.
- Suggest she attend her next adult clinic appointment with a Peer Educator. She can also take a friend with her for support.
- See "Appendix 12A: Transition Checklist for Healthcare Workers" for additional activities to support Mary's transition.
- **What types of activities could healthcare workers do with, or suggest to the client, to assist with his or her transition to adult care?**
  - Participants will discuss.
- **What follow up could healthcare workers provide once the adolescent is enrolled in the adult clinic?**
  - If you have a Peer Educator, that person can meet Mary and accompany her to her next adult clinic appointment.
  - Link Mary with an older adolescent who has transitioned successfully to the adult clinic. Maybe this person can even function as her treatment buddy.
  - Even if Mary is not being seen by your clinic medical staff, can you see her once or twice more for counselling and support? If so, make an appointment for a follow-up visit. Plan to see Mary after her next appointment at the adult clinic (the same day or the following day), to find out how it went.

### **Case Study 3:**

Betty is 20 years-old and is a client at the paediatric clinic where you work. Betty has been diagnosed with some learning problems and developmental delays. Although she should transition to the adult clinic soon because of her age, you have some concerns about her development and ability to independently manage her own care. You are afraid she will get “lost” at the adult clinic. How do you proceed with Betty?

#### **Key points for trainers: Betty**

- **What fears or concerns do you think this client has about transitioning to adult care?**

It is difficult to know what fears or concerns Betty has as they are not articulated in the case study. We know what your fears and concerns are, but not Betty’s. Participants will discuss this question.

- **What could healthcare workers do to prepare this client for transition to adult care?**

- Discuss the transition with Betty, find out from her what she thinks about it. Address her fears.
- Encourage her to attend any presentations or meetings during which transitioning care will be the main topic.
- Take Betty for a tour of the adult clinic. Get her feedback on the clinic.
- Identify a healthcare worker at the adult clinic who is particularly good with clients who have developmental delays, introduce Betty to this healthcare worker, find out if this healthcare worker can take a lead in managing Betty’s care.
- Get Betty ready to take on a greater responsibility for her own care. Does she know which medications she takes? If not, tell her and check her understanding later to help her remember.
- Right now, how does she remember to take her evening or morning ARVs? If her caregiver has to remind her, what can Betty do to wean herself from her caregiver’s reminder and start remembering on her own?
- During Betty’s last medical visit to your clinic, make sure she has a copy of her medical record and enough medications to take her to her first appointment at the new clinic. Again, ask her the names of her medications to help her remember; praise her when she successfully cites the names of the drugs she is taking. Ensure she is taking more and more responsibility for remembering her appointments and taking her medicines.
- Once Betty starts feeling comfortable with the adult clinic, start transferring her medical care. For her first visit she should be accompanied by a Peer Educator (if available) with whom she feels comfortable. Maybe this Peer Educator should accompany her the second time as well.

- Stay in touch with Betty, provide her with counselling support out of your clinic, so that she can remain connected with your clinic until she feels comfortable in the adult clinic.
  - Ensure that Betty has a youth support group with whom she should keep in touch with as she makes the transition (so that **something** in her care does not change during this period of adjustment).
  - Given Betty's special circumstances, take the transition particularly gradually, even if it takes a year.
- **What types of activities could healthcare workers do with, or suggest to the client, to assist with his or her transition to adult care?**
    - As noted above, pre-transition tours of the adult clinic, assistance from the Peer Educator (if available) and support groups, emotional and psychosocial support from healthcare workers in the paediatric clinic.
  - **What follow up could healthcare workers provide once the adolescent is enrolled in the adult clinic?**
    - For this particular case, you would want to keep in touch with both Betty and her adult clinic healthcare workers for at least 6 months to monitor her progress and adjustment.
    - If possible, meet with Betty at least a couple of times after the transition to see how it is going. Plan to meet her the day of, or the day after, her first and second adult clinic appointments.



### Trainer Instructions

**Step 7:** Allow 5 minutes for questions and answers on this session.



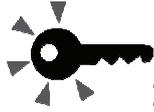
### Trainer Instructions

Slides 26-27

**Step 8:** Ask participants what they think the key points of the module are. What information will they take away from this module?

**Step 9:** Summarise the key points of the module using participant feedback and the content below.

**Step 10:** Ask if there are any questions or clarifications.



## **Module 12: Key Points**

- In some places, adolescents will have attended paediatric clinics, where they may have been getting services since birth or for many years. After a certain age, they usually have to transition to the adult ART clinic. This care transition can be difficult for the adolescent — not only is it a matter of adjusting to a new, less nurturing environment and to new healthcare workers, but adult clinics expect that their clients take on responsibility for their own care. Taking on a greater role in self-care and self-advocacy may be challenging for the adolescent, depending on their level of development and maturation.
- Healthcare workers should help ALHIV set and achieve goals for independence and self-management of care as a way of recognising the young person's increasing maturation, capacity to make choices, and independence.
- Not all ALHIV will be ready to make the transfer to adult care at the same age. Healthcare workers must take into account their cognitive and physical development, their emotional maturity, their support at home and in the community, and their health status.
- It is possible for adolescents to have a smooth transition to adult care and receive adolescent-friendly services in the adult clinic. Key factors that support successful transition include: an agreed transition plan that gives the ALHIV time to prepare for the transition and to take on more responsibility for self-care, an adult clinic that is willing to meet the special needs of adolescents and is staffed with healthcare workers who understand the special needs of ALHIV.

## Appendix 12A: Transition Checklist for Healthcare Workers

This checklist contains the key points related to preparing older adolescents to transition to adult care. This checklist is meant to assist healthcare workers or other members of the multidisciplinary care team by outlining the basic steps involved in supporting adolescents with the transition process. The checklist provides suggested subjects for discussion, although additional areas may be identified to meet individual adolescent's needs. In the 'Action' section, the healthcare worker should record major actions undertaken, referrals made or information — such as medical records — given to the adolescent or caregiver during the discussion.

✓	<b>Important steps and suggested activities to facilitate the transition process</b>	<b>Actions and comments</b>
	<b>1. Introduce the transition</b>	
	Introduce and discuss transition during adolescent support group meetings and group health education sessions	
	Discuss transition during clinical check ups and individual counselling sessions with adolescent clients	
	Discuss transition with caregivers, during group or individual sessions	
	<b>2. Encourage the adolescent to assume increasing responsibility for his or her own health care management</b>	
	Assure the adolescent understands his or her own health condition, care plan, and medications	
	Talk about transition and transfer to the adult clinic, discuss expectations, and answer any questions	
	Talk to adolescents about general coping, positive living, and building supportive relationships	
	Give caregivers an opportunity to discuss their feelings about transition and any concerns about having a less active role in the adolescent's care	
	<b>3. Assess client's ability to make independent health care decisions, assess readiness for the transition, and determine additional support needs</b>	
	Assess <i>client's</i> understanding of own care and transition process (for example, using an assessment method such as quiz, questionnaire, discussion, etc.)	
	Assess <i>caregiver's</i> understanding of own care and transition process	
	If usually accompanied by family members, encourage the adolescent to make their next appointment (on their own) and to refill their medications also on their own	
	Initiate any needed referrals, including to support groups	

	<b>4. Provide anticipatory guidance</b>	
	Review plans for continued adherence to care	
	Review adherence to medicines and ensure the client has, and knows how to use, a medicine calendar or other system of keeping track of doses	
	Ensure client knows where to access help/assistance, if he or she has questions about the new clinic	
	<b>5. Implement the transfer to an adult clinic</b>	
	Send copies of reports, letters, and tests to the adolescent and caregivers so they have their own records	
	Transfer medical records	
	Discuss the adolescent's care with healthcare workers at the adult clinic	
	Provide orientation to the adolescent, ideally with the healthcare workers or member of the multidisciplinary team in the adult clinic	
	Follow up after the transfer (for example, schedule a follow-up visit with the adolescent, encourage Peer Educators to visit the adult clinic and talk with newly transitioned adolescents, etc.)	
	<b>6. Other activities that may help healthcare workers and ALHIV plan for the transition process</b>	
	Meet with an adolescent client who has transitioned to adult care	
	Schedule a visit to the adult clinic, so adolescents can learn more about the services and the healthcare providers before the transfer takes place	
	Attend a support group session with other transitioning adolescents	
	Suggest trying journaling activities, to address transition and issues such as future goals	
	Use a comprehension assessment tool (for example, quiz, questionnaire, etc.) about HIV and adherence to care and medications to assess readiness	

## **Appendix 12B: Transition Resources for Healthcare Workers and ALHIV (for Adaptation)**

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### **Resources for Providers:**

<http://hivcareforyouth.org/pdf/TransitioningYouth.pdf>

This is a comprehensive guide for healthcare providers. It includes many tools and resources and is designed for perinatally infected youth, but broadly applicable.

<http://www.aids-ed.org/aidsetc?page=etres-display&resource=etres-272>

This curriculum slide set is designed to provide an introduction to issues adolescents who have perinatally acquired HIV infection face. It uses a developmental approach to explore issues from the perspective of the adolescent, the family, and the healthcare provider.

### **Resources for ALHIV (teaching self advocacy/encouraging independent health behaviour):**

<http://www.aids-ed.org/aidsetc?page=etres-display&resource=etres-269>

Youth-friendly workbook for adolescent patients to assist with the transition from a paediatric care setting.

### **Reference Articles:**

Blum, R. 1995. *Transition to adult health care: Setting the stage*. Journal of Adolescent Health, 17, 3-5.

Kelly, A. 1995. The primary care provider's role in caring for young people with chronic illness. *Journal of Adolescent Health*, 17, 32-36.

Scal, P., Evans, T., Blozis, S., Okinow, N. & Blum, R. 1999. *Trends in transition from pediatric to adult health care services for young adults with chronic conditions*. Journal of Adolescent Health, 24, 259-264.



# Module 13 Monitoring, Evaluation, Quality Improvement, and Supportive Supervision



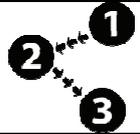
**Total Module Time:** 135 minutes (2 hours, 15 minutes)

## Learning Objectives

**After completing this module, participants will be able to:**

- Discuss the importance of routinely monitoring adolescent HIV care and treatment activities.
- Discuss how information from monitoring and evaluation can be used to support programme improvement.
- Describe the purpose of Quality Improvement (QI).
- Define and describe supportive supervision.

## Methodologies



- Interactive trainer presentation
- Large group discussion
- Small group work

## Materials Needed



- Slide set for Module 13
- Flip chart and markers
- Tape or Bostik
- A couple of pocket calculators for Exercise 1. (Participants who have cell phones may have calculators on their phones, so the trainer may not need to supply more than 1 or 2 pocket calculators.)
- Photocopies (one for each participant) of all forms and registers used to monitor adolescent HIV care and treatment services. A partial listing of these forms is included on page 12 in this module. It may also be helpful to have samples of forms and registers that have been completed (with all identifying information removed to preserve client confidentiality), as well as written instructions on how to complete the registers and forms.
- The trainer should have the slide set for Module 13.
- Participants should have their Participant Manuals. The Participant Manual contains background technical content and information for the exercises.



### References and Resources



- Republic of Zambia, Ministry of Health. 2010. *National Training Package on Provider-Initiated Paediatric HIV Testing & Counselling in Zambia*.
- Republic of Zambia, Ministry of Health. 2010. *Guidelines for Antiretroviral Therapy for HIV in Infants and Children in Zambia, Second Edition*.
- Republic of Zambia, Ministry of Health. 2008. *Zambia Paediatric HIV Care Training Course*.

### Advance Preparation



- Read through the entire module and ensure that all trainers are prepared and comfortable with the content and methodologies.
- Exercise 1 requires advance preparation. Please review the exercise ahead of time.
- Gather and photocopy all forms and registers used with adolescent clients, so that each person has a copy.
- If possible, also bring samples of completed forms and registers to serve as examples for participants.

### **Session 13.1: Monitoring, Evaluation, and Data Collection**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation and large group discussion	40 minutes
Exercise 1: Using Data for Decision-making: Small group work and large group discussion	50 minutes
Questions and answers	5 minutes
<b>Total Session Time</b>	<b>95 minutes</b>

### **Session 13.2: Quality Improvement and Supportive Supervision**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation and large group discussion	25 minutes
Questions and answers	5 minutes
Review of key points	10 minutes
<b>Total Session Time</b>	<b>40 minutes</b>

## Session 13.1      Monitoring, Evaluation, and Data Collection

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**Total Session Time:**      95 minutes (1 hour, 40 minutes)



### **Trainer Instructions**

Slides 1-4

**Step 1:**      Begin by reviewing the Module 13 learning objectives and the session objectives, listed below.

**Step 2:**      Ask participants if there are any questions before moving on.

### **Session Objectives**

**After completing this session, participants will be able to:**

- Discuss the importance of routinely monitoring adolescent HIV care and treatment activities.
- Discuss how information from monitoring and evaluation can be used to support programme improvement.



### **Trainer Instructions**

Slides 5-17

**Step 3:**      To encourage participants to think about the role of monitoring and evaluation in health care, ask the following questions:

- *Why do you think it is important to keep records and monitor our work with adolescents?*
- *Do you know how the data (information) that you record is used at the facility level and at the national level?*
- *Have you ever received feedback from district health managers on the monitoring data you or your clinic submit?*

Make the point that often, healthcare workers spend a lot of time filling in registers and preparing monthly or quarterly statistics and reports without a clear understanding of what good this will do. They also may receive little or no feedback on the monthly forms and reports they submit. Ask participants how this makes them, or other healthcare workers feel about spending so much time on monthly reports.

Explain that it is important for healthcare workers to know that their facility reports are aggregated up to the district and

national levels, and also form part of international progress reports, such as UNICEF's annual "Towards Universal Access," among others.

**Step 4:**

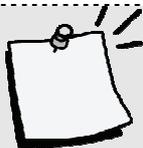
Then ask:

- *What are "targets"? Can you give an example of a target?*
- *What are "indicators"? Can you give an example of an indicator?*

Explain that indicators are central to a monitoring system. Define indicators and give examples of indicators used to monitor adolescent care and treatment services as you go along. Then ask:

- *What is "evaluation"? What questions might an evaluation answer?*

Discuss evaluation as a way of assessing the change in indicator measurements and stress the importance of measuring indicators over time. For example, at the beginning of an adolescent programme, you can measure indicators to collect baseline values. Then, subsequent measurements allow you to measure changes in indicators over time. Determining whether indicator measurements remain stable or change over time provides important information.



**Make These Points**

- Monitoring and evaluation is the standardised process by which data related to the delivery of HIV services is collected and evaluated. This data can be used to monitor progress in the implementation of adolescent care and treatment services from the facility perspective, in addition to the evaluation conducted at the district and national levels.
- Monitoring is the routine collection and tracking of key programme data over time.
- Targets are specific goals established before a new programme or service is implemented or established at specific times (for example, annually setting targets for the number of adolescents enrolled and retained in care).
- Indicators provide information about key service interventions. Indicators can be calculated for facility, district, or national levels depending on need and how the data will be used. It is important to monitor and evaluate changes in indicators over time.
- Evaluation is the process of tracking changes in indicators that reflect service delivery and determining whether pre-established targets are reached.
- Monitoring and evaluation are continuous processes, not a one-time event.

## Monitoring

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Monitoring is the routine collection and tracking of key programme data over time. Monitoring is a process that helps to identify problems early so that they can be corrected quickly. This requires that data be collected, compiled, and analysed on a routine basis.

Healthcare workers play a vital role in the monitoring process by regularly collecting (by recording), compiling and reporting data to determine, for example, the number of adolescents enrolled in HIV care and receiving ART, the number of adolescents retained in care over time, and the types of clinical and support services offered to adolescents.

### Monitoring and evaluation of adolescent HIV care and treatment programmes can help to:

- Assess whether the programme is meeting its targets, and
- Identify and improve problem areas in the implementation of adolescent HIV care and treatment services.

Routine monitoring and evaluation are necessary to gather information on:

- **Individual outcomes**, such as: Is she responding to treatment? Is she being retained in care? Is he adhering to his medicines? Is he receiving the comprehensive care and support services he needs?
- Care and treatment **programme outcomes**, such as: Is the programme retaining adolescent clients in care? Are all eligible adolescents receiving ART? Are routine lab tests and clinical follow-up visits being conducted on schedule?). Programme outcomes are usually the cumulative tally of individual outcomes and can give insight into strengths and areas needing improvement within the individual facility or in a district.

## Targets

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**Targets** are specific goals established before a new programme or service is implemented and on a regular basis thereafter. For example, a target may be “To ensure that 95% of eligible adolescent clients initiate ART.”

## Indicators

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- Indicators are summary measures used to help indicate the status of your programme’s activities.
- Indicators measure things such as the number of adolescent clients tested and informed of their HIV status, the number enrolled in HIV care, and of those, the number initiating ART. See Table 13.1 for more examples of indicators.
- Paediatric and adult HIV care and treatment indicators are established on a national level according to the needs, resources, and standards of the programme. Indicators are often defined in the national strategic plan for HIV.

- National level indicators generally cover service delivery to PLHIV, quality of care, and management-related information.
- Though indicators are identified at the national level, they can be calculated for facility, district, or national levels depending on need and how the data will be used.
- Some facilities will have their own indicators in addition to the national indicators. Facility-level indicators can help to identify progress, problems, challenges, and solutions in the delivery of adolescent HIV care and treatment services at a specific site. For example, facility level indicators could show how many adolescents are missing appointments and of these, how many are followed up and returned to care.
- Indicators may need to be revised periodically (for example, in response to changes in national guidelines for the programme or services being monitored).
- Indicators reflect a certain timeframe — for example the month, the quarter, or the year.
- It is important to measure changes in indicators over time. So, for example if the number of HIV-infected adolescent enrolled in care as 20 in 2000, 40 in 2002, and 30 in 2004, then we can see that performance in 2004 was very poor (in comparison to 2002).

**Table 13.1: Examples of adolescent HIV care and treatment indicators**

- |   |
|---|
| <ul style="list-style-type: none"> <li>• Number HIV-infected adolescents (age 10–19) enrolled in care</li> <li>• Number of adolescents who initiated ART</li> <li>• Number of adolescents currently receiving ART</li> <li>• Number of adolescents who had a change of therapy</li> <li>• Number of adolescents for whom ART was discontinued</li> <li>• Number of adolescents lost to follow-up</li> <li>• Number of adolescents transferred to other facilities</li> <li>• Number of adolescents who have died</li> <li>• Number of adolescents who have become pregnant</li> </ul> |
|---|

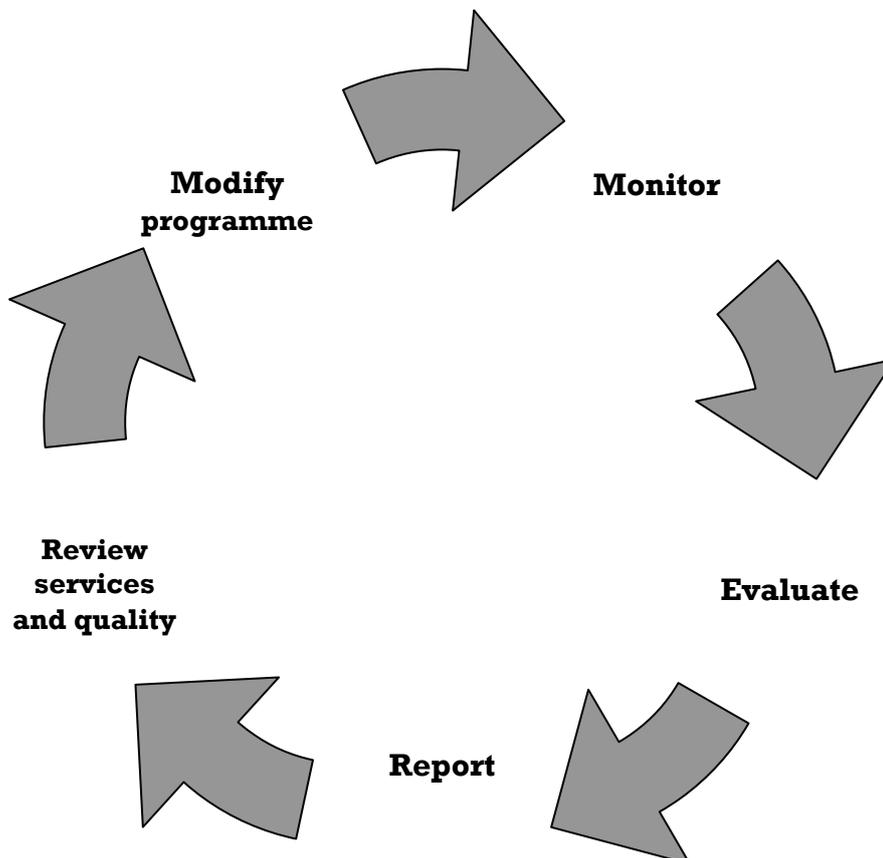
## Evaluation

While monitoring helps look at progress in indicators and helps us know if we are reaching our targets, evaluation examines the process in greater depth and helps us understand what the indicators are really telling us.

- Evaluations are typically conducted at specific time periods (for example, at the end of the year), whereas monitoring happens on a daily, monthly, and quarterly basis.
- An evaluation of the adolescent HIV care and treatment programme will demonstrate how well the programme has met the expected goals and targets. So, for example, an evaluation might help to answer the following questions:
  - Are adolescents enrolled in the programme living longer than those not enrolled in care?
  - Are adolescents enrolled in the programme experiencing a better quality of life?

- Has the programme reduced the number of adolescents hospitalised for HIV-related illnesses?
  - How might the programme be improved to reach its targets and goals more quickly?
  - What are the barriers to reaching our goal?
- Evaluations should be conducted regularly to look at changes that occur as the adolescent HIV programme is implemented and maintained. For example, has the ALHIV hospitalisation rate changed from 2008 to 2010? If so, can this change be attributed to our programme? This will enable programme staff to identify areas of programme strength and weakness (“review services and quality” in Figure 13.1) and to respond to weaknesses by investigating and correcting problems (“modify programme” in Figure 13.1).
  - The monitoring and evaluation process is a continuous one, as shown in Figure 13.1, below.

**Figure 13.1: Monitoring and evaluation as a continuous process**



Source: Republic of Zambia Ministry of Health. 2010. *National Training Package on Provider-Initiated Paediatric HIV Testing & Counselling in Zambia*.



### Trainer Instructions

Slides 18-21

#### Step 5:

Discuss reporting, focusing on the use of monitoring data to complete monthly reports and how summary data can be used to evaluate services. Ask participants:

- *At your clinic, how are the monthly summary forms and monthly reports completed? (Who completes them? Where do they get the information from to complete them?)*
- *To whom are they submitted?*
- *These reports are analysed at the district, but who at your clinic analyses them as well?*
- *What is done with information in these monthly reports? Is it ever used to improve/modify services? Who has an example?*



### Make These Points

- Monitoring and evaluation is an ongoing, continuous process that informs the planning and implementation of changes to improve the delivery of adolescent HIV care and treatment services.
- Indicators are calculated using routinely collected data that are recorded in registers and summarised on monthly summary forms.
- Local staff need to review the monthly reports to ensure activities are on target to meet annual goals. Programme successes and weaknesses need to be communicated back to staff to initiate discussion on how weaknesses can be addressed.

## Reporting

Individual client data is recorded in **registers**. Data in the registers is tallied and the totals recorded on the **monthly summary forms**. The figures on the monthly summary forms summarise a facility's progress on key indicators (such as those listed in Table 13.1). The monthly summary forms are then submitted to the district level. The districts collate (that is, put together the monthly summary forms from all of the district clinics) the monthly summary forms and submit the collated data to the national level.

The monthly summary form should be compiled into a **monthly report** for local staff to review how the programme is doing. The monthly report for the facility might include data in addition to that which was reported to the district (such as that collected on retention from appointment books or wait times).

All staff must be aware of the importance of accurately completing registers. The monthly summary forms and reports are accurate only if the registers are completed correctly and consistently. This is discussed further in the next session.

## Programme Modification

At every level of the system (facility, district, and national) monthly summary forms should prompt discussion on how the programme can be modified, or improved, to better meet targets. (This activity is referred to as “review services and quality” in Figure 13.1.) So, for example if the most recent annual report indicated that 45% of ALHIV clients were lost to follow-up last year and the target was to reduce loss to follow-up to no more than 10%, we would know that the programme needs to be modified, or improved in order to reach the target. Such programme improvements will require discussion of:

- **What is the problem:** Why is loss to follow-up so high? How can we find out? Can we interview our clients? Shall we interview clients that have dropped out of care? Shall we interview our staff to find out more? What will we ask them? Shall we ask them not only why the problem exists but also what they think are the potential solutions?
- **How will we address the problem:** Once the key problems have been identified, how will these problems be addressed?
- **Decide on a plan:** Once the key solutions and specific actions have been identified, *who* will address the issue, by *when* and using what *funding* (if funding is needed).
- **How will we decide if the plan is working:** How will we know if the new initiative is working? Will we look at this year’s firstly quarterly summary form? Is so, what improvement do we expect to see? Will we consider the program modifications successful if our loss to follow up drops to 40%? (Probably not.) How about 15%? (Probably, but with recognition that further improvement is needed.)



### Trainer Instructions

Slides 22-25

**Step 6:** Provide an overview of the standard HIV care and treatment record keeping systems. Note that the information from monitoring is only as useful as the completeness and accuracy of the information collected in the data collection tools (forms and registers).

**Step 7:** Discuss the characteristics of effective monitoring and evaluation systems (content in text box) and then summarise the standardised forms used to provide data on HIV care and treatment for adolescents. National guidelines dictate the use of national forms and registers so that methods for collecting, monitoring, and evaluating data are standardised across all levels of the health system (at primary, secondary, and tertiary levels) across the country.

Provide a copy of commonly used registers and forms for each participant. It may also be helpful to have samples of forms and registers that have been completed, as well as written

instructions on how to complete the registers and forms. Remind participants that they will have a chance to practise filling in these forms and registers as a part of the practicum sessions.



### Make These Points

- Standard national forms and registers are used to collect and document key adolescent HIV care and treatment services. These national tools are periodically revised and updated based on changes in national HIV guidelines. So, it is important to check that your facility is using the most updated versions.
- Patient confidentiality must be maintained. All records, including registers, must be kept in a secure location and no identifying data should leave the site.
- Ensuring that data are collected and recorded accurately, completely, and reliably on standardised forms according to established procedures is the responsibility of the staff members that conduct these duties.
- Follow-up systems for patient tracking are recommended to support adherence to care and medicines.

## Adolescent HIV Care and Treatment Data Collection

Standard data collection and accurate recording of activities and outcomes are essential. **Data collection for adolescent HIV care and treatment is part of the existing national system and uses existing national HIV care and treatment forms and registers; it is not a separate system with adolescent-specific forms.**

In most cases, adolescent data will be captured in the national forms for paediatric HIV, meaning that the same system and tools can be used to describe, monitor, and evaluate both the paediatric HIV programme and the adolescent programme. However, if an adolescent client is provided with care in an adult HIV clinic (either because he or she has been transitioned to the adult HIV clinic or because paediatric services are unavailable), then facilities should use the national forms for adult HIV care and treatment to report activities related to the ALHIV.

**Systems for documenting care and treatment activities must also maintain client confidentiality. All records, including registers, must be kept in a secure location and no identifying data should leave the site.**

It is the responsibility of all staff members that complete registers or summary forms to ensure that data is accurate and complete and that data

collection protocols are followed. Attention to accuracy will help to ensure that monthly, quarterly and annual reports accurately reflect services and activities conducted in the clinic.

**The following is a list of some of the key registers and forms facilities use to monitor activities in their adolescent programmes**

(note that this list assumes adolescents are being captured on paediatric registers and forms, adapt as needed if adolescents will only be seen in adult clinics):

- Ward or clinic registers
- General HIV counselling and testing register
- Patient care card
- HIV care summary sheet
- Paediatric clinical follow-up form
- Paediatric ARV eligibility form
- Paediatric adherence form
- Pharmacy logbook/register
- Patient status form
- TB diagnostic worksheet and TB screening tool
- Paediatric patient locator form

**Characteristics of effective M&E systems**

Effective monitoring and evaluation systems require record keeping that is:

- **Accurate** — that is, correct and true. So if the client's CD4 is 401, ensure that "401" is entered correctly in the appropriate cell against his or her identifying code or name
- **Reliable** — completed the same way every time
- **Standardised** — recorded using the same tools (for example the same register, using the same abbreviations, formulas, and definitions) in every clinic across the district or country
- **Recorded** following established guidelines

## **Tracking Missed Appointments**

Health facilities also use an **appointment book** to keep track of upcoming appointments and if appointments were missed. A follow-up system should be developed to contact adolescent clients and their caregivers when appointments are missed and try to bring the adolescent back into care.

**A follow-up system requires:**

- A working appointment system whereby healthcare workers can readily track missed appointments and contact clients (and caregivers) who miss appointments to bring them back to the clinic.
- In urban areas, contact may involve the use of cell phones (calling, SMS) while in rural areas, community workers, NGOs, Peer Educators, family members, or friend networks may serve this purpose.
- Contacting clients and families when appointments are missed, either by telephone or by home visit, requires the consent of the adolescent client and/or the caregiver; therefore, a system should be in place to both obtain contact information and to routinely request consent to follow-up missed appointments.



### Trainer Instructions

Slides 26-29

**Step 8:** Facilitate Exercise 1 to give participants a chance to review and discuss a data sample that could have come from an adolescent HIV care and treatment programme.

### Exercise 1: Using Data for Decision-making: Small group work and large group discussion

<b>Purpose</b>	<ul style="list-style-type: none"> <li>To review adolescent HIV care and treatment data and analyse the data for use in programme decision-making</li> </ul>
<b>Duration</b>	50 minutes
<b>Advance Preparation</b>	<ul style="list-style-type: none"> <li>Review and analyse the sample quarterly adolescent HIV care and treatment report (<b>Table 13.2</b>), review all calculations to ensure you understand them.</li> <li>Bring in calculators so that the small groups can calculate percentages for the sample data set. Participants with cell phones may have calculators on their phones.</li> </ul>
<b>Introduction</b>	This will be a chance for participants to review and analyse a sample of adolescent care and treatment data. Regular analysis of programme data provides the information needed to identify gaps and weaknesses in services and indicates where effort is needed to make improvements.
<b>Activities</b>	<p><b>Small Group Work</b></p> <ol style="list-style-type: none"> <li>Break participants into small groups.</li> <li><b>Part 1 of small group work:</b> Give the groups about 20 minutes to review the data in <b>Table 13.2</b> (below) and answer the following questions: <ul style="list-style-type: none"> <li>For which indicators is Clinic Make Believe doing well and meeting their targets? How do you know?</li> <li>For which indicators is Clinic Make Believe NOT meeting its targets? How do you know?</li> <li>If the number of adolescents enrolled in care in Q4 (the 4<sup>th</sup> quarter) of 2009 was 450 and the number of adolescents receiving ART was 290, would you say that in 2010 they are doing better or worse enrolling clients in ART?</li> <li>Which areas should Clinic Make Believe staff focus on improving?</li> </ul> </li> <li><b>Part 2 of small group work:</b> Ask the groups to take another 10 minutes to identify one of the areas that need improvement at Clinic Make Believe and then discuss: <ul style="list-style-type: none"> <li>What is the problem?</li> <li>How should we (assuming we are the managers at</li> </ul> </li> </ol>

	<p style="text-align: center;">Clinic Make Believe) address the problem?</p> <p>The trainer should circulate between the small groups during the discussion to respond to questions and correct any misconceptions.</p> <p><b>Small Group Presentations and Large Group Discussion</b></p> <ol style="list-style-type: none"> <li>4. Reconvene the large group. Ask the first small group to report on part 1. Ask other groups to comment on whether or not they agree and why.</li> <li>5. Ask another group to report on part 2 of the small group work. Encourage discussion on these two questions as answers can vary.</li> <li>6. Ask if any other small group chose a different indicator (than that already reported on) to discuss in Part 2, if so, ask that group to report as well. Encourage discussion on their answers to the discussion questions.</li> <li>7. (optional) Ask the adolescent co-trainer to comment on the ways facilities can involve ALHIV in the review and analysis of routinely collected data, with a view to identify gaps and improve services.</li> </ol>
<b>Debriefing</b>	<ul style="list-style-type: none"> <li>• A close review of the data in routine (monthly, quarterly or annual) summary reports can provide much information about the strengths and weaknesses of a programme.</li> <li>• In reviewing summary reports, you need to compare the current period's data with that from the previous period or against targets. Otherwise you won't know if the data represents an improvement or a decline in services.</li> <li>• When comparing raw data against targets, calculate percentages (use the current period figures as the numerator and the target as the denominator) to get a better sense of progress or to compare with earlier periods (months, quarters or years).</li> </ul>

**Note to trainers:** the “% of Target” column and percent figures in the “2010, Q4” column (Table 13.2) do not appear in the Participant Manual!

**Table 13.2: Sample data for Exercise 1**

<b>Quarterly adolescent HIV care and treatment summary report for Clinic Make Believe</b>			
<b>Number of adolescents enrolled in care</b>	<b>2010, Q4</b>	<b>Target*</b>	<b>% of Target</b>
• Age 10–14, female	100		
• Age 10–14, male	95		
• Age 15–19, female	150		
• Age 15–19, male	165		
• Total	510	550	93%
<b>Number of adolescents receiving ART</b>	<b>2010, Q4</b>	<b>Target*</b>	<b>% of Target</b>
• Age 10–14, female	75		
• Age 10–14, male	70		
• Age 15–19, female	102		
• Age 15–19, male	120		
• Total	367	350	105%
<b>Number of new adolescent clients in the quarter</b>	<b>2010, Q4</b>	<b>Target*</b>	<b>% of Target</b>
• Age 10–14, female	1		
• Age 10–14, male	2		
• Age 15–19, female	22		
• Age 15–19, male	12		
• Total	37	40	93%
<b>Number of adolescent clients who missed appointments in the quarter</b>	<b>2010, Q4</b>	<b>Target*</b>	<b>% of Target</b>
• Age 10–14, female (75 had appointments this quarter)	20 (27%)		
• Age 10–14, male (70 had appointments this quarter)	23 (33%)		
• Age 15–19, female (95 had appointments this quarter)	37 (39%)		
• Age 15–19, male (105 had appointments this quarter)	42 (40%)		
• Total (345 had appointments this quarter)	122 (35%)	10% of those in care, max	35% vs 10%, they are doing poorly
<b>Number of adolescent clients attending support group meetings</b>	<b>2010, Q4</b>	<b>Target*</b>	<b>% of Target</b>
• Age 10–14, female	55		
• Age 10–14, male	45		
• Age 15–19, female	120		
• Age 15–19, male	130		
• Total	350	50% of those in care	69% vs 50%, they are doing well
<b>Number of support group meetings held at the clinic</b>	<b>2010, Q4</b>	<b>Target*</b>	<b>% of Target</b>
• For 10–14 year olds	6		
• For 15–19 year olds	10		
• For caregivers	3		
• Total	19	9	211%
<b>Number of active adolescent Peer Educators at the clinic</b>	<b>2010, Q4</b>	<b>Target*</b>	<b>% of Target</b>
Number of active adolescent Peer Educators at the clinic	15	6	250%

\*Target is based on 2009 figures as well as national and funder goals. If a cell is blank it means that sub-targets have not been stated.

## **Exercise 1: Using Data for Decision-making: Small group work and large group discussion**

### **Part 1 of small group work**

- **For which indicators is Clinic Make Believe doing well and meeting their targets? How do you know?**

Clinic Make Believe is doing very well in the following areas:

- Number of adolescents receiving ART
- Number of adolescent clients attending support group meetings
- Number of support group meetings held at the clinic
- Number of active adolescent Peer Educators at the clinic

- **For which indicators is Clinic Make Believe NOT meeting its targets, how do you know?**

Clinic Make Believe is not meeting its targets for those indicators that are circled in the column on the right:

- Number of adolescents enrolled in care
- Number of new adolescent clients in the quarter
- Number of adolescent clients who missed appointments in the quarter

- **If the number of adolescents enrolled in care in Q4 (the 4th quarter) of 2009 was 450 and the number of adolescents receiving ART was 290, would you say that in 2010 they are doing better or worse enrolling clients in ART?**

In Q4 of 2010 Clinic Make Believe had 367 of 510 patients enrolled in ART (about 71%). In Q4 of 2009 they had 290 of 450 patients on ART, which is about 64%. In 2010 they had a higher percentage of their clients on ART, so we can say that they did better in 2010 (in comparison to 2009) enrolling clients in ART. Note that numbers had to be translated into percentages before they could be compared.

- **Which areas should Clinic Make Believe staff focus on improving?**

All three of the above areas, but the indicator where the most work is needed in the last one: Number of adolescent clients who missed appointments in the quarter

**Part 2 of small group work: Assuming the small groups want to focus on “Number of adolescent clients who missed appointments in the quarter”, responses to discussion questions are as follows (please note, some of the groups may choose to work on either of the other two indicators for which Clinic Make Believe did poorly):**

- **What is the problem?**

Participants will discuss, but there could be any number of things going on: maybe the clinic doesn't have an appointment system, or even if they do, maybe the clinic doesn't have a tracking system, or if they do have a patient tracking system, maybe data from it is not analysed or followed up. Does the clinic need to hire someone to track those who

miss appointments? Someone who could make phone calls, send SMS messages and also make home visits? But maybe the problem has more to do with accessibility (maybe the clinic is far from town with no mass transportation), staff attitude, lack of youth-friendly services, or maybe services are offered at times when young people are not available.

Maybe you need a bit more information to find out exactly who is not attending their appointments, for example:

- Is the missed appointment rate any different by age or gender (answer: Males have a slightly higher missed appointment rate and the older age groups have a higher missed appointment rates).
  - Is the missed appointment rate lower for those on ART? This information would be interesting to know, but data is not available in this summary report to calculate it. For the next quarter, consider collecting information on ART status of those who have missed their appointments.
  - Interview healthcare workers and clients who have dropped out of care to find out why they are missing their appointments. Ask them for ideas to attract them back into care.
- **How should we (assuming we are the managers at Clinic Make Believe) address the problem?**  
It depends on the problem. Participants will discuss.



### **Trainer Instructions**

**Step 9:** Allow 5 minutes for questions and answers on this session.

## Session 13.2      Quality Improvement and Supportive Supervision

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**Total Session Time:**      40 minutes



### **Trainer Instructions** Slides 30-31

**Step 1:**      Begin by reviewing the session objectives listed below.

**Step 2:**      Ask participants if there are any questions before moving on.

### **Session Objectives**

**After completing this session, participants will be able to:**

- Describe the purpose of Quality Improvement (QI).
- Define and describe supportive supervision.



### **Trainer Instructions** Slides 32-38

**Step 3:**      Ask participants to discuss these questions:

- *What does “quality” mean to you when you think about adolescent HIV care and treatment services?*
- *How do you think facility managers would define quality?*
- *What about adolescent clients? How would they define quality?*
- *How do you think monitoring and evaluation and QI are related? (Possible response: monitoring data indicate where there are weakness and gaps in service; use QI initiatives to address these weaknesses.)*

Make the point that everyone has a different perspective on what quality means and that we need to consider all of these perspectives, as well as national guidelines and indicators on quality, when developing plans to measure and improve quality of our services.

**Step 4:**      Define Quality Improvement. Emphasize the different but related goals of QI versus monitoring and evaluation and that both are integral to supporting effective, high quality adolescent HIV care and treatment programmes.

- Step 5:** When providing an overview of the methods used to assess quality, give examples of what QI activities might evaluate (for example, the youth friendliness of services as well as compliance with national guidelines and standard operating procedures). Then ask participants:
- *What methods do you think you would use if you wanted to find out if, for example, your clinic's adherence preparation visits were adequate?* (Possible response: compare the content of our clinic's session with the national checklist, get feedback from clients, ask clients questions to find out what they learned, etc)

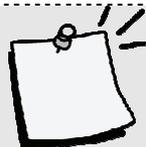
Write their ideas on flip chart. Add other ideas, as needed, to provide a full discussion of various methods for conducting QI.

(optional) Ask the adolescent co-trainer to give his or her thoughts on the ways adolescents can be involved in QI activities.

- Step 6:** Explain that supervisors may identify (or confirm) shortfalls in individual, team, or departmental practice through QI reviews. QI activities are most effective when the focus is on addressing deficiencies by providing staff with guidance and mentorship, as well as group problem solving techniques.

Ask participants (including the adolescent co-trainer) to discuss possible solutions/interventions to the following problems identified through QI activities:

- Older adolescents often miss their clinic appointments.
- There is an increase in the number of adolescent clients presenting with STIs.
- Many younger adolescent clients have not been fully disclosed to and therefore do not understand why they need to take medicines every day.
- Adolescent clients think the support group is a "waste of time" and regular attendance is low.



### **Make These Points**

- Quality Improvement is the means by which activities are routinely evaluated to check that the services offered by the multidisciplinary team are following the established guidelines and standard operating procedures.
- The purpose of QI is to identify problems (in service delivery, in data, or in both) so that they can be corrected, thereby improving services for adolescent clients and their families.

- QI should be a routine part of the normal functioning of health facilities on an ongoing basis.
- A variety of methods may be used to conduct QI. Methods may include:
  - Periodic reviews of records
  - Direct observation of healthcare workers' (and Peer Educators') activities
  - Assessments of youth-friendliness of services, for example using the tool in Module 2
  - Individual interviews or focus groups with adolescent clients and caregivers
  - Involvement of ALHIV, such as Peer Educators, in routing QI activities
- It is important to set up time for multidisciplinary teams and managers to discuss QI findings and issues, and plan the way forward, for example through quarterly meetings.

## **Quality Improvement**

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Quality Improvement is the means by which activities are routinely evaluated to check that the services offered by the multidisciplinary team are following the established guidelines and standard operating procedures. QI is also referred to as quality assurance (QA). The purpose of QI is to identify problems so that they can be corrected, thereby improving services for adolescent clients and their caregivers.

QI should be a routine part of the normal functioning of health facilities. QI incorporates procedures in which all staff, at all levels, not solely supervisors, should be involved.

## **Methods to Assess Quality**

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It is often necessary to use a variety of methods to assess programme quality. Standard monitoring tools such as patient forms and registers capture only a fraction of services provided to adolescents, and provide no information on the quality of those services. For example: If only forms, client records, and registers were used to assess quality, there would be no information on the quality and youth-friendliness of clinical services, or of psychosocial support, adherence, and other counselling sessions, or of referrals made to community-based support services.

### **QI activities might, for example, examine and evaluate:**

- Quality and youth-friendliness (see Module 2) of services
- Compliance with national guidelines, standard operating procedures and protocols for HIV care and treatment
- Adequacy of space and attention to privacy and confidentiality
- Linkages to ongoing support and community-based services

QI activities may vary somewhat from one facility to the next based on the type of facility and the facility's experience with adolescent HIV care and treatment services.

### **QI activities may include, for example:**

- Periodic reviews of records, with staff feedback — the reviewer should check for accuracy, completeness, and consistency of entries in the various forms, registers, and patient files.
- Direct observation of clinical procedures and counselling sessions.
- Periodic assessments of youth-friendliness of services, including youth participation (the checklist presented in Module 2 could be used to periodically assess youth-friendliness).
- Interviews with staff indirectly or directly involved in the adolescent care and treatment programme to obtain feedback on specific indicators. A case conference format may be used as a forum to highlight current challenges, systems that are working, and those that need improvement and provide a forum for proposing solutions.
- Individual interviews or focus groups with adolescent clients who receive care and treatment services at the clinic. For example, do adolescent clients feel that adequate information and support was provided in the counselling sessions? Did they feel welcomed at the clinic? Were they treated non-judgementally by healthcare workers? Were they clear about what was expected of them, for example, how and when to follow-up? Were their other health and psychosocial needs assessed and addressed (for example, sexual and reproductive health services)? Was their privacy and confidentiality respected?
- Individual interviews or focus groups with caregivers of adolescent clients who attend the clinic. For example, do caregivers feel that they were provided with adequate information on supporting the adolescent at home?
- Client exit interviews or anonymous surveys by clients.
- Evaluation of physical space, client flow, and time concerns through observation and staff and client interviews.
- Meeting with representatives of services where adolescent clients and caregivers are referred. Ask them about client needs, gaps in services, and feedback on services.

### **How often should QI be conducted?**

During initial implementation, daily or weekly QI activities allow for immediate follow-up to correct identified problems. As the services become established, reviews should become a formal part of overall adolescent HIV care and treatment programme monitoring activities at designated intervals (monthly progressing to quarterly reviews). Although supervisors have the ultimate responsibility for QI, the activities related to QI should be shared with other members of the team.

It is important to set aside time for multidisciplinary team members and managers to discuss QI findings and issues and jointly come up with

solutions and ideas for quality improvement. This can be accomplished, for example, as a part of routine monthly multidisciplinary team meetings or through dedicated quarterly meetings on QI review.



### **Trainer Instructions**

Slides 39-45

#### **Step 7:**

Ask participants:

- *What are the qualities you believe should be associated with “supportive supervision”?*
- *For example, if you were expanding adolescent care and treatment services within your facility, what could your supervisor do to support you and help you to set up these services in line with national care and treatment guidelines?*

Write responses on flip chart. Ask participants:

- *Do you think using supportive supervision would improve performance of healthcare workers who are being supervised?*

If any participants have experienced or provided supportive supervision, ask them to share their experiences.

#### **Step 8:**

(optional) Ask the adolescent co-trainer to comment on the types of supportive supervision he or she thinks adolescent Peer Educators need, based on experience if possible.

#### **Step 9:**

Give an overview of supportive supervision, discussing the aims of supportive supervision. Highlight that supportive supervision is important to healthcare workers, as well as to Peer Educators.



### **Make These Points**

- An important component of responding effectively to QI findings is to provide supportive supervision. Supportive supervision is an approach to QI that requires collaboration between the supervisor and the staff. The supervisor must work with staff to:
  - Establish goals.
  - Monitor performance.
  - Identify and correct problems.
- The goals of supportive supervision are to:
  - Obtain valuable information on programme functioning and quality.
  - Facilitate on-site, participatory problem-solving.
  - Improve healthcare worker (or Peer Educator) performance by providing one-to-one support to address an identified deficiency

and to equip them with new skills or competencies.

- Acknowledge the healthcare worker's (and Peer Educator's) contribution to the success of the programme.
- Involve both supervisors and healthcare workers (and volunteers, such as Peer Educators) to improve service provision.
- Involve youth to give feedback and improve service provision.
- Assure the programme is successful in meeting the needs of ALHIV and their caregivers and families.
- Motivate staff and volunteers.

## Supportive Supervision

Quality Improvement activities are not complete without assessing the results of the QI review and planning a response. Often weaknesses discovered through QI activities require supervisors to work with staff (including adolescent Peer Educators) to address the problems. An important component of responding effectively to QI findings is to provide **supportive supervision**.

Supportive supervision requires the supervisor to work with staff to establish goals, monitor performance, identify and correct problems, and proactively improve the quality of adolescent HIV care and treatment services through training, one-to-one support, mentoring, and coaching.

### Focus of QI

QI is most effective when the focus is on providing guidance and mentorship, as well as group problem solving techniques, to assist healthcare workers to correct problems and overcome barriers to a high quality programme.

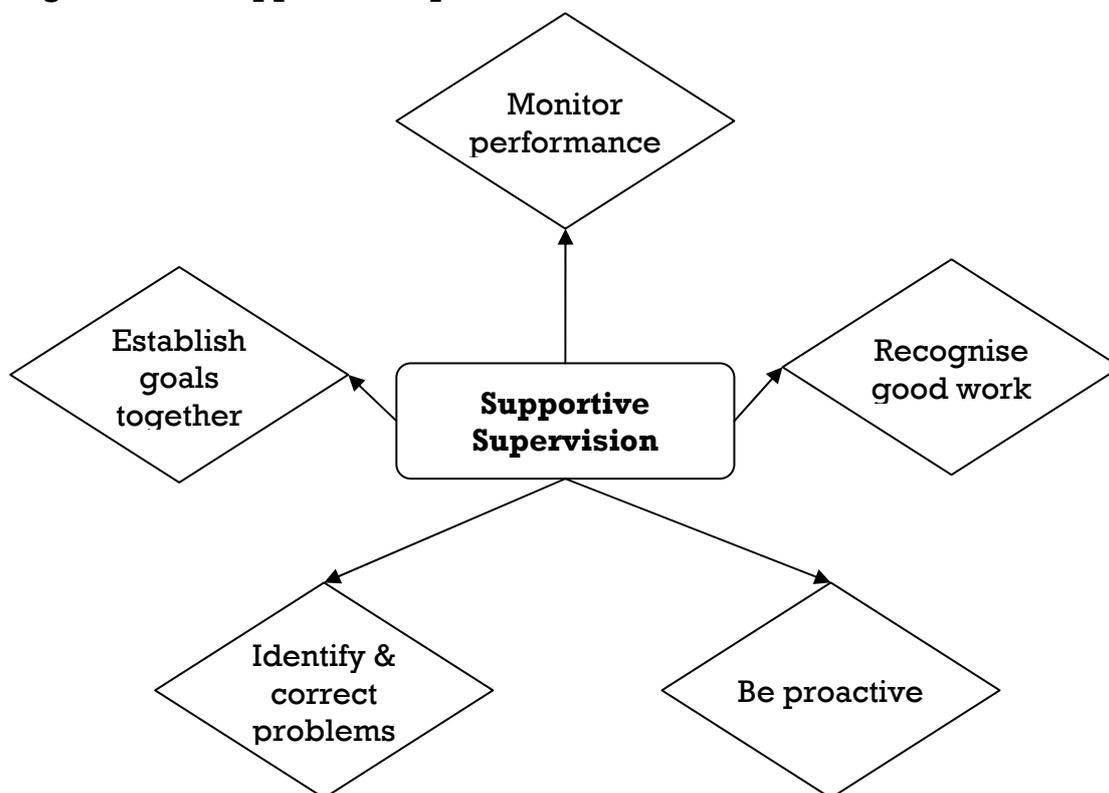
It is important that supervisors explain to their staff that QI activities are not simply the responsibility of supervisors, but rather that all activities conducted by any staff member that aims to improve services are a part of the continuous QI process.

### Supportive supervision aims to:

- Obtain valuable information on programme functioning and quality.
- Improve healthcare worker performance by providing one-to-one support to address an identified deficiency.
- Acknowledge good practices by providing positive feedback and noting contributions to the success of the programme.
- Involve supervisors, healthcare workers, and adolescents themselves (such as adolescent Peer Educators) to improve service provision (it is not the sole responsibility of the supervisor). Healthcare workers and Peer Educators can support each other by mentoring their peers.
- Facilitate on-site, participatory problem-solving. Healthcare workers should be encouraged to become comfortable actively participating with their supervisors to address weaknesses.
- Assure the programme is successful in meeting the needs of ALHIV and their caregivers and families.
- Motivate staff.

Once a deficiency in service provision is identified, supportive supervision must be established as quickly as possible to prevent poor practices from becoming routine. “Figure 13.2: Supportive supervision” illustrates the concept of supportive supervision.

**Figure 13.2: Supportive supervision**



**Trainer Instructions**

**Step 10:** Allow 5 minutes for questions and answers on this session.



**Trainer Instructions**

Slides 46-49

**Step 11:** Ask participants what they think the key points of the module are. What information will they take away from this module? Remind participants that they will have a chance to practise data collection more in the clinical practicum, and that they will have a chance to plan more about QI and supportive supervision during the action planning session.

**Step 12:** Summarise the key points of the module using participant feedback and the content below.

**Step 13:** Ask if there are any questions or clarifications.



## Module 13: Key Points

- Monitoring and evaluation is the standardised process by which data related to the delivery of services is collected and evaluated. This data can be used to monitor progress in the implementation of adolescent care and treatment services from the facility perspective.
- Indicators provide information about key service interventions. Indicators can be calculated for facility, district, or national levels depending on need and how the data will be used. Indicators are calculated using routinely collected data that are recorded in registers and summarised on monthly summary forms.
- A review of the monthly forms that summarise monitoring data can help to identify service strengths and weaknesses. Programme successes and weaknesses need to be communicated back to staff to initiate discussion on how weaknesses can be addressed.
- Quality Improvement is the means by which activities are routinely evaluated to check that the services offered by the multidisciplinary team are following the established guidelines and standard operating procedures. Services not following established procedure, once identified, can be corrected. Information that supports QI activities includes that from monitoring and evaluation processes.
- A variety of methods may be used to conduct QI, including:
  - Periodic reviews of records
  - Direct observation of healthcare workers' (and Peer Educators') activities
  - Assessments of youth-friendliness of services
  - Individual interviews or focus groups with adolescent clients and caregivers
- An important component of responding effectively to QI findings is to provide supportive supervision. Supportive supervision requires collaboration between the supervisor and staff to:
  - Establish goals.
  - Monitor performance.
  - Identify and correct problems.



# Module 14 Supervised Clinical Practicum



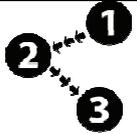
**Total Module Time:** Approximately 2–2.5 days

## Learning Objectives

**After completing this module, participants will:**

- Be familiar with the core competencies needed to provide adolescent HIV care and treatment services.
- Feel prepared for the clinic-based practical sessions.
- Be able to demonstrate core competencies in adolescent HIV care and treatment services in a clinical setting.
- Discuss and debrief on the practicum sessions.
- Identify their own strengths and weaknesses in providing adolescent HIV care and treatment services, and plan for ongoing practice and mentorship.

## Methodologies



- Interactive trainer presentation
- Large group discussion
- Supervised practicum sessions
- Small group work

## Materials Needed



- Slide set for Module 14
- Flip chart and markers
- Tape or Bostik
- Extra copies of “Appendix 14B: Practicum Checklist”
- Participants should have their Participant Manuals. The Participant Manual contains background technical content and information for the exercises.

## References and Resources



- George, J.H., & Doto, F.X. 2001. A simple five-step method for teaching clinical skills. *Family Medicine*, 33, 577-8.

## Advance Preparation



### General preparation

- Read through the entire module and ensure that all trainers are prepared and comfortable with the content and methodologies for the practicum.



**Clinic selection**

- Select a clinic for the practicum sessions, ideally a setting where there are many ALHIV who need services. This could be in a paediatric clinic or an adult clinic where young people receive services — but the most important thing is that there are ALHIV clients present during the practicum times.
- Get a sense of daily activities at the site as well as adolescent client flow and number; discuss with site leadership the best way for participants to observe and practise applying the skills they have learned with adolescent clients.
- The curriculum suggests 2 days for the practicum, but this can be adjusted as needed, based on the clinic schedule, preceptor and participant availability, and the time available.

**Preparing clinic staff**

- Ideally, advance preparation for the practicum should be initiated at least 1 month in advance and include at least 3 meetings. 2 of the 3 meetings are in the healthcare facility: one with leadership and the other with clinical staff who have agreed to assist as preceptors. The third meeting is with the preceptors alone — where you can orient them on what will happen during the practicum.
- Meet with site leadership and staff in advance to discuss the training and the supervised practicum sessions.
  - Discuss the possibility that some of the facility staff will take on roles as preceptors during the practicum sessions (this is in addition to the trainers, who will also be preceptors).
  - If agreed, work with site leadership to identify the facility staff who are experienced and able to support participant learning.

**Orient preceptors**

- Orient preceptors on methods of coaching, mentoring, and giving feedback if they are new to this type of training. Review “Appendix 14A: Tips on Mentoring and Coaching with Preceptors” with them.
- Discuss the key skills taught in training. Discuss with preceptors what participants will get out of the practicum and how their role as preceptor during the practicum can facilitate the learning of new skills.
- Review the practicum checklist in “Appendix 14B: Practicum Checklist” and decide how participants will practise the key skills. For example, if participants are to

	<p>practise leading group education sessions with adolescents, this must be arranged in advance, adolescent clients must be present, a space for the talk identified, etc.</p> <ul style="list-style-type: none"> <li>• Photocopy “Appendix 14B: Practicum Checklist”. Preceptors should have one checklist for each participant in their group (plus a few extra copies just in case). Preceptors will fill in the checklist for each participant throughout the course of the supervised practicum.</li> <li>• Let preceptors know if they will be responsible for evaluating participant performance. Discuss how to fill in the Practicum Checklist with examples of “Good,” “Fair” and “Poor” performance for several of the competencies.</li> <li>• Discuss with preceptors the possibility of debriefing daily with the participant(s) assigned to her or him during the practicum.</li> <li>• If time allows, role play with preceptors various scenarios that can occur during the practicum, so that they can learn how to deal with difficult situations involving participants.</li> </ul> <p><b>Logistics</b></p> <ul style="list-style-type: none"> <li>• Arrange for transport to and from the practicum site(s) and lunch for participants and preceptors.</li> <li>• Plan for the participants to reconvene for lunch during each of the practicum days.</li> <li>• Organise a room for the daily debriefing. Inform participants where and when the group will reconvene each day for the daily practicum debriefing.</li> <li>• Gather a summary of the lessons and accomplishments from preceptors to share during Exercise 2, Practicum Session Debrief. Remember that this information must be generally applicable to the group rather than to one single individual.</li> </ul>
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### **Session 14.1: Practicum Planning and Preparation**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation and large group discussion	40 minutes
Questions and answers	10 minutes
Total Session Time	50 minutes

### **Session 14.2: Supervised Clinical Practicum and Debrief**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation	5 minutes
Exercise 1: Supervised Clinical Practicum and Daily Practicum Debrief	2 days
Exercise 2: Final Practicum Debrief : Small and large group discussion	60 minutes
Questions and answers	5 minutes
Total Session Time	Approximately 2–2.5 days

## Session 14.1      Practicum Planning and Preparation

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**Total Session Time:**      50 minutes



### **Trainer Instructions**

Slides 1-4

**Step 1:**      Begin by reviewing the Module 14 learning objectives and the session objective, listed below.

**Step 2:**      Ask participants if there are any questions before moving on.

### **Session Objectives**

**After completing this session, participants will:**

- Be familiar with the core competencies needed to provide adolescent HIV care and treatment services.
- Feel prepared for the clinic-based practical sessions.



### **Trainer Instructions**

Slide 5

**Step 3:**      Introduce the practicum to participants and explain that this is the time they will get to practise in a clinical setting the information and skills they have learned over the past couple of weeks.

Introduce new preceptors that may be joining the group.

**Step 4:**      Ask participants the following questions:

- *Have you participated in practicum sessions as a part of other trainings?*
- *What was helpful about these practicum sessions and what could have been done better?*
- *What are your expectations for this practicum session on adolescent HIV care and treatment?*



### **Make These Points**

- The supervised practicum is a chance for participants to apply that

which they have learned in the training to their clinic-based practice.

- It is a chance for healthcare workers to ask questions and to get the experience that will allow them to feel more comfortable initiating activities for ALHIV at their sites.



### **Trainer Instructions**

Slides 6-7

**Step 5:** Review the practicum logistics and assignment of participants to preceptors. Allow time for questions.

**Step 6:** Refer participants to “Appendix 14B: Practicum Checklist”. Go over the key skills participants will be asked to demonstrate during the practicum, using the checklist as a guide. Remind participants that they may not have an opportunity to practise all of these skills during the formal practicum session, but that they will receive continued mentorship and support after the training.

Ask participants if there are skills or areas on the practicum checklist that they do not feel comfortable with or for which they need review. Take the time needed to review content areas and skills, pulling in lessons learned from the case studies or reviewing key content information as needed.

**Step 7:** Lead a discussion about conduct, confidentiality, and client consent during the practicum.

**Step 8:** Lastly, discuss plans for the daily practicum debrief sessions, as well as for the final practicum debrief on the last day of the training. All trainers, preceptors and participants should attend the debriefing sessions.



### **Make These Points**

- During the practicum session, participants will be asked to demonstrate knowledge, skills, and ability regarding the core competencies in ALHIV care and treatment.
- Be kind, friendly, and courteous when interacting with clients, caregivers, healthcare workers, and managers at the health facility. Remember confidentiality is of the utmost importance. Discussions and observations made during the practicum should only be shared with other participants, trainers, or preceptors in your practicum group. If there is need to discuss the case with the wider group for learning purposes, always maintain patient confidentiality by changing names and any other identifying information.

## Core Competencies

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Participants will be asked to practise and demonstrate a number of skills learned during the training. Refer to “Appendix 14B: Practicum Checklist” for more information on the core competencies for healthcare workers.

Preceptors will be available to help and mentor participants as they master the skills learned in training.

## Conduct during the Practicum Session

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- Remember that we are guests at the health facility and must respect the wishes of the healthcare workers and managers who work in the facility.
- Keep all discussions and observations during the practicum confidential. Only share with other participants, trainers, or preceptors, and *only* for learning purposes. When discussing cases after the practicum, change any identifying information about specific individuals so that no one will be able to guess who is being described.
- *Always* inform the preceptor if you need to take a break or leave the facility for any reason during the practicum.
- *Always* introduce yourself to other healthcare workers and clients. Tell them that you are currently on a course about care and treatment services for adolescents, and that the training includes observation and practice in the health facility.
- *Always* ask adolescent clients and their caregivers for their verbal consent to observe or practise. Keep in mind that clients have the right to refuse to give consent or to withdraw their consent at any time. Participants and preceptors are obligated to concede to the client’s request.
- *Always* ask the preceptor if you have a question or a concern.

Preceptors will be using “Appendix 14B: Practicum Checklist” to assess participant performance during the practicum. Become familiar with the content of this form, including how the preceptors will make a final evaluation.



### Trainer Instructions

**Step 9:** Allow 5 minutes for questions and answers on this session.

## Session 14.2 Supervised Clinical Practicum and Debrief



**Total Session Time:** Approximately 2 days



### Trainer Instructions

Slides 8-9

**Step 1:** Begin by reviewing the session objectives listed below.

**Step 2:** Ask participants if there are any questions before moving on.

### Session Objectives

**After completing this session, participants will:**

- Be able to demonstrate core competencies in adolescent HIV care and treatment services in a clinical setting.
- Discuss and debrief on the practicum sessions.
- Identify their own strengths and weaknesses in providing adolescent HIV care and treatment services, and plan for ongoing practice and mentorship.



### Trainer Instructions

Slides 10-11

**Step 3:** Lead participants through Exercise 1 — the supervised practicum session, which will take place over 2 days in a health facility serving adolescent clients.

### Exercise 1: Supervised Clinical Practicum and Daily Practicum Debrief

<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To practise core competencies needed to provide adolescent HIV care and treatment services in a clinical setting</li> </ul>
<b>Duration</b>	Approximately 2 days (adjust as needed)
<b>Advance Preparation</b>	<ul style="list-style-type: none"> <li>• See the “Advance Preparation” section, which starts on page 14-1.</li> </ul>
<b>Introduction</b>	The supervised clinical practicum will allow participants the chance to practise and apply skills learned during the training.
<b>Activities</b>	1. Assign each participant to a preceptor. There should be no more than 4–5 participants assigned to each

	<p>preceptor.</p> <ol style="list-style-type: none"> <li>2. Participants should practise as many of the core competencies as possible, listed in “Appendix 14B: Practicum Checklist” during the course of the practicum session.</li> <li>3. Preceptors should observe and mentor participants to correctly conduct each skill. Preceptors should note which skills each participant was able to practise during the day on the Practicum Checklist (a checklist should be completed for EACH participant). Note any comments or areas that need improvement on the checklist.</li> <li>4. Suggest to participants that they complete the Practicum Checklist for themselves, noting which core competencies were conducted and any comments. Extra copies of the checklist should be made available.</li> </ol> <p><b>Optional:</b> At the discretion of the trainer, participants may rotate so that they have at least one session with a different preceptor. The checklist can be used as a communication tool so that a new preceptor is aware of skills that have been practised and those that need more work.</p>
<p><b>Daily Debriefing</b></p>	<p>Participants should reconvene as a large group at the end of each practicum day. During the daily practicum debrief, ask participants:</p> <ul style="list-style-type: none"> <li>• <i>What core competencies did you practise during the day?</i></li> <li>• <i>Which competencies were the most comfortable for you to conduct? Which were the most challenging?</i></li> <li>• <i>Are there areas in which you feel you need more practice? Which ones?</i></li> <li>• <i>Were there any unexpected or new things that you observed today during the practicum session?</i></li> <li>• <i>Do you have suggestions to improve tomorrow’s practicum session?</i></li> </ul> <p><b>Optional:</b> If previously discussed and agreed upon with preceptors, participants may also discuss these questions with their preceptors, individually, or as a small group as time allows at the end of each day.</p>



**Trainer Instructions**  
Slides 12-13

**Step 4:** When the practicum is completed, reconvene participants and lead Exercise 2, which will provide opportunity to debrief the supervised clinical practicum session.

<b>Exercise 2: Final Practicum Debrief : Small and large group discussion</b>	
<b>Purpose</b>	<ul style="list-style-type: none"> <li>To share experiences and lessons learned during the multi-day practicum.</li> </ul>
<b>Duration</b>	60 minutes
<b>Advance Preparation</b>	<ul style="list-style-type: none"> <li>See the “Advance Preparation” section, which starts on page 14–1.</li> </ul>
<b>Introduction</b>	This debrief will provide an opportunity for participants to discuss their practicum experiences and learn from each other.
<b>Activities</b>	<p><b>Small Group Discussions:</b></p> <ol style="list-style-type: none"> <li>Break up participants into small groups. Mix participants so that they are NOT with people who were in their practicum group (where possible). The objective of this exercise is to encourage participants from each of the practicum groups to interact and share.</li> <li>Give each group a flip chart and markers. Ask them to discuss and note responses to the following questions: <ul style="list-style-type: none"> <li><i>What was your overall experience during the practicum?</i></li> <li><i>What skills were the most difficult to perform?</i></li> <li><i>What skills were less difficult?</i></li> <li><i>In which areas would you like more mentoring in the future?</i></li> <li><i>What did you learn that you had not anticipated learning?</i></li> <li><i>What was your most memorable experience from the practicum?</i></li> <li><i>How can participants and preceptors continue to support one another in building their skills once the training is over?</i></li> </ul> </li> <li>Give the small groups about 30 minutes for the discussion.</li> </ol> <p><b>Large Group Discussion:</b></p> <ol style="list-style-type: none"> <li>Bring the large group back together and ask each of the small groups to briefly present key points of their small group discussions. The facilitator should note on flip chart the following key points: <ul style="list-style-type: none"> <li>Areas where participants want more mentoring</li> <li>How participants and preceptors can continue to support one another</li> </ul> </li> <li>If possible, present a summary of the preceptors’ overall experiences during the clinical practicum session. Note that individual participant performance should not be discussed in the large group. Instead, present key observations during the practicum</li> </ol>

	including strengths and areas that still need improvement. Preceptors can suggest ways for participants to continue building their skills after returning to their sites.
<b>Debriefing</b>	<ul style="list-style-type: none"> <li>• Congratulate participants on a job well done during the practicum session. Remind participants that they will need to continue practising these skills when they return to their health facilities and as they work with adolescent clients. Encourage participants to help mentor each other, as well as other healthcare workers at their facility, in order to provide quality, youth-friendly HIV care and treatment to ALHIV and their family members.</li> </ul>



### **Trainer Instructions**

**Step 5:** Allow 5 minutes for questions and answers on this session.

## **Appendix 14A: Tips on Mentoring and Coaching with Preceptors**

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### **What are the qualities of a good preceptor?**

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- Strong knowledge, skills, and experience related to adolescent HIV care and treatment
- Professional
- Understands the importance of skill sharing and capacity building and is therefore willing to teach and to mentor
- Respects others
- Conscientious and trustworthy
- Accountable for her or his work; responsive to feedback
- Upholds confidentiality at all times
- Ethically sound decision making
- Leadership

### **Preceptor Do's and Don'ts**

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#### **Do:**

- Make participants feel welcome and valued.
- Set shared achievable goals.
- Put yourself in the participant's shoes.
- Ask questions that show interest in developing participants' skills.
- Monitor progress and give feedback frequently.
- Provide guidance, encouragement and support.

#### **Don't:**

- Appear unprepared.
- Be vague about your expectations.
- Confine the participant to passive roles.
- Leave feedback to the final assessment.
- Embarrass or humiliate participants.
- Accept behaviour that is unethical or unsafe.
- Judge if a participant does not know something.

#### **Five-step method for teaching clinical skills**

1. Provide an overview of the skill and how it is used in patient care.
2. Demonstrate exactly how the skill is conducted without commentary.
3. Repeat the procedure, but describe each step.
4. Have participant "talk through the skill" by detailing each step.
5. Observe and provide feedback to the participant as he or she performs the skill.

Adapted from: George, J.H., & Doto, F.X. 2001. A simple five-step method for teaching clinical skills. *Family Medicine*, 33, 577-8.

## Appendix 14B: Practicum Checklist

This checklist includes many of the core competencies taught during the training. The checklist can be used during the practical sessions of the training and, **after the training it can also be a useful tool for supervisors and healthcare workers in the adolescent clinic.** It is unlikely that participants will be able to practise and demonstrate all of the competencies in this checklist during the 2 day practicum, but the checklist can be used when participants return to their sites after training, as part of supportive supervision and mentoring activities.

**Preceptor instructions:** Use one checklist per participant in your group. As you observe a skill, tick your rating as GOOD, FAIR or POOR. Record any comments or recommendations in the right-hand column; be prepared to share comments with the participant. Use this checklist to complete the final evaluation for each participant. **Participant instructions:** Complete this checklist during the practicum with your assessment of your own performance. In the “Comment” column, record areas for improvement or further study.

**Name of Participant:** \_\_\_\_\_ **Dates of Practicum:** \_\_\_\_\_

**Name of Preceptor(s):** \_\_\_\_\_ **Name of Health Facility:** \_\_\_\_\_

CORE COMPETENCIES	PRECEPTOR or SELF-RATING (TICK ONE)			COMMENTS
	GOOD	FAIR	POOR	
<b>Clinical care of ALHIV skills</b>				
Observes at least 1 baseline clinical assessment				
Observes at least 1 follow-up clinical assessment				
Conducts at least 1 baseline medical and social history				
Conducts at least 1 interval medical and social history				
Demonstrates familiarity with national HIV guidelines — identifies criteria for ART initiation, failure, and prophylaxis in adolescents				

CORE COMPETENCIES	PRECEPTOR or SELF-RATING (TICK ONE)			COMMENTS
	GOOD	FAIR	POOR	
Assesses growth and nutrition (weight, height) for at least 1 client				
Assesses WHO clinical stage of at least 1 client				
Performs at least 1 general physical examination on each of the following: 1. Pre-pubertal female 2. Pre-pubertal male 3. Post-pubertal female 4. Post-pubertal male				
Performs at least 1 SRH examination on each of the following: 1. Post-pubertal female 2. Post-pubertal male				
Prescribes CTX correctly to at least 1 eligible client				
Conducts at least 1 screening for tuberculosis				
Prescribes isoniazid preventive therapy (IPT) correctly to at least 1 eligible client				
Demonstrates knowledge of which laboratory tests to request and the timing of those requests				
<b>Communication and counselling skills</b>				
Effectively presents health education session/health talk to a group of clients or caregivers				
Ensures privacy and explains confidentiality to adolescent clients				
Uses active listening skills when speaking with adolescent clients				

CORE COMPETENCIES	PRECEPTOR or SELF-RATING (TICK ONE)			COMMENTS
	GOOD	FAIR	POOR	
Uses gestures and responses to show interest when talking with adolescent clients				
Uses open-ended questions when communicating with and counselling adolescent clients				
Empathizes with the adolescent client and shows understanding				
Avoids words that sound judging when communicating with adolescent clients				
Uses reflection skills during counselling sessions				
Summarises main points of a counselling session and help the adolescent client set goals				
Tailors counselling according to age and developmental stage of the adolescent				
<b>Psychosocial support for ALHIV</b>				
Conducts at least 1 psychosocial assessment and completes a Psychosocial Assessment form				
Suggests positive and practical ways to cope when a client expresses psychosocial concerns				
Offers practical suggestions to clients to cope with and fight stigma and discrimination				
<b>Mental health and ALHIV</b>				
Screens for mental health well being during routine check-up				
Identifies serious mental health problems and provides support or refers appropriately, using suggested guidance or algorithms				
Gives practical support to ALHIV who are experiencing mild mental health problems, such as mild anxiety or				

CORE COMPETENCIES		PRECEPTOR or SELF-RATING (TICK ONE)			COMMENTS
		GOOD	FAIR	POOR	
sadness					
<b>Disclosure support</b>					
Assesses caregiver's readiness for disclosure to child and counsels caregiver on the importance of disclosure					
Conducts at least 1 disclosure support session with caregiver on disclosing to the child/adolescent					
Conducts at least 1 disclosure support session with ALHIV on disclosing his or her status to others					
Offers follow-up disclosure support to adolescent clients and caregivers through the disclosure process					
<b>Adherence support</b>					
Explains the importance of adherence to adolescent clients in understandable terms					
Conducts at least 1 ART readiness assessment with adolescent who is starting ART and caregiver					
Conducts all 3 of the standard adherence preparation visits (1 time each) with adolescent and/or caregiver					
Provides individualised counselling to make an adherence plan with client and caregiver					
Provides follow-up adherence support and counselling to at least 1 client on ART and to at least 1 caregiver whose child is on ART.					
<b>Positive living</b>					
Provides accurate, age-appropriate, and comprehensive positive living counselling to ALHIV					
Provides accurate information and counselling on positive prevention					

CORE COMPETENCIES	PRECEPTOR or SELF-RATING (TICK ONE)			COMMENTS
	GOOD	FAIR	POOR	
Provides nutrition counselling and support to at least 1 client				
Provides accurate information and counselling on personal and home hygiene to clients and caregivers				
Asks clients about alcohol and drug use and provides accurate risk reduction counselling				
<b>Sexual and reproductive health</b>				
Provides non-judgemental counselling about adolescent sexuality and SRH issues				
Conducts an SRH risk assessment and provides non-judgemental, accurate sexual risk reduction counselling				
Provides accurate, non-judgemental counselling and information on ways to practise safer sex				
Provides condoms to clients and accurately demonstrates male and female condom use				
Provides adolescent-friendly STI counselling, screening, and treatment for male and female clients				
Provides accurate, non-judgemental counselling on safe childbearing				
Provides accurate, non-judgemental contraceptive counselling and supplies (and/or referrals)				
Provides accurate, non-judgemental PMTCT counselling and services				
Provides PMTCT counselling and information; refers pregnant ALHIV for PMTCT services				
<b>Community linkages</b>				
Understands how to establish linkages with other agencies, including community-based organisations				

CORE COMPETENCIES	PRECEPTOR or SELF-RATING (TICK ONE)			COMMENTS
	GOOD	FAIR	POOR	
Provides appropriate referrals to clients and follows-up on those referrals				
<b>Transition to adult care</b>				
Provides counselling and support to ALHIV to prepare them for taking on a greater role in their self-care in preparation for transitioning to adult care				
<b>Monitoring and evaluation</b>				
Correctly completes essential registers and forms				
Understands how monitoring data can be used to identify strengths and weaknesses of services				

**FINAL EVALUATION BY PRECEPTORS:**

**Name of participant:** \_\_\_\_\_

**Tick one:**

- \_\_\_\_\_ Demonstrated a majority of core competencies effectively and is ready to start providing adolescent HIV care and treatment services in a clinical setting
- \_\_\_\_\_ Demonstrated some core competencies effectively, but still needs more practice before providing adolescent HIV care and treatment services in a clinical setting
- \_\_\_\_\_ Unable to demonstrate most skills and should participate in the training course again before providing adolescent HIV care and treatment services in a clinical setting

**Additional comments:**

**Preceptor(s) signature(s):** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Date:** \_\_\_\_\_



# Module 15 Action Planning, Course Evaluation, and Closure



**Total Module Time:** 180 minutes (3 hours)

## Learning Objectives

**After completing this module, participants will:**

- Have reviewed the key steps and considerations to initiate or scale-up of adolescent HIV care and treatment services.
- Have started development of a site-specific action plan to initiate or improve adolescent HIV care and treatment services.
- Have identified the potential challenges to implementing adolescent HIV care and treatment services at their site and potential solutions to those challenges.
- Have discussed whether or not the training objectives have been achieved.
- Have reflected on the concerns, expectations, and strengths discussed on the first training day.
- Have listed next steps, including training follow up and supportive supervision.
- Have completed the training post-test.
- Have evaluated the training and given suggestions for improvement.

Methodologies	
	<ul style="list-style-type: none"> <li>• Interactive trainer presentation</li> <li>• Large group discussion</li> <li>• Small group work</li> <li>• Post-test</li> <li>• Training evaluation</li> </ul>

Materials Needed	
	<ul style="list-style-type: none"> <li>• Slide set for Module 15</li> <li>• Electronic version of “Appendix 15A: Adolescent HIV Care and Treatment Action Planning and Implementation Template” on flash drive so that participants with laptop computers can work in the electronic version rather than on paper</li> <li>• Flip chart and markers</li> <li>• Tape or Bostik</li> <li>• Participants should have their Participant Manuals. The Participant Manual contains background technical content</li> </ul>



	<p>and information for the exercises.</p> <ul style="list-style-type: none"><li>• Extra copies of “Appendix 15A: Adolescent HIV Care and Treatment Action Planning and Implementation Template” (several per group, in case participants need extra copies)</li><li>• Training completion certificates for each participant</li></ul>
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**References and Resources**



- None for this module.

**Advance Preparation**



- Read through the entire module and ensure that all trainers are prepared and comfortable with the content and methodologies.
- Prepare training completion certificates for each participant.
- Invite a guest speaker to give participants their training completion certificates and close the training (optional).
- If possible, make a few extra copies of “Appendix 15A: Adolescent HIV Care and Treatment Action Planning and Implementation Template”.

### **Session 15.1: Site-Specific Adolescent HIV Care and Treatment Implementation and Action Planning**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation	10 minutes
Exercise 1: Action Planning: Small group work and large group discussion	80 minutes
Questions and answers	5 minutes
Total Session Time	95 minutes

### **Session 15.2: Reflection on Training Objectives and Concerns, Expectations, and Strengths**

<b>Activity/Method</b>	<b>Time</b>
Interactive trainer presentation and large group discussion	30 minutes
Total Session Time	30 minutes

### **Session 15.3: Post-test, Training Evaluation, and Closing**

<b>Activity/Method</b>	<b>Time</b>
Post-test	25 minutes
Exercise 2: Training Evaluation: Individual work	15 minutes
Presentation of training certificates and closing	15 minutes
Total Session Time	55 minutes

# Session 15.1      Site-Specific Adolescent HIV Care and Treatment Implementation and Action Planning

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**Total Session Time:**      95 minutes (1 hour, 35 minutes)



## **Trainer Instructions** Slides 1-5

- Step 1:**      Begin by reviewing the Module 15 learning objectives and the session objectives, listed below.
- Step 2:**      Ask participants if there are any questions before moving on.

## **Session Objectives**

### **After completing this session, participants will:**

- Have reviewed the key steps and considerations to initiate or scale-up of adolescent HIV care and treatment services.
- Have started development of a site-specific action plan to initiate or improve adolescent HIV care and treatment services.
- Have identified the potential challenges to implementing adolescent HIV care and treatment services at their site and potential solutions to those challenges.



## **Trainer Instructions** Slides 6-9

- Step 3:**      Remind participants that this training is only the first step in improving and expanding HIV care, treatment, and support services for adolescent clients. Explain that during this session, participants will work together to plan the specific actions they will take once they complete the training and go back to their facilities to implement what they have learned.
- Remind participants that the action plan created in this session should be reviewed with facility managers and supervisors, and should complement any existing workplans the facility has developed.

**Step 4:** Ask participants:

- *What do you think are the key steps to improving or expanding services for ALHIV at your health facility?*

If they need a hint, remind them that this was discussed in Module 2, and that scale up typically starts with an assessment of need. Give them time to come up with the other steps (which are summarised below, but listed in more detail in “Table 2.1: Making services more youth-friendly” in Module 2).

Briefly review some of the key steps participants should keep in mind when they create their own site-specific action plan in the next exercise.

- Step 5:** Ask participants if they can recall the key characteristics of youth-friendly HIV care and treatment services, discussed in Module 2. After participants give inputs, revisit the key characteristics in Table 15.1 — participants might recognise this table from Module 2. Again, they should keep these characteristics in mind as they start working on Exercise 1.



**Make These Points**

- It is important to first assess where we are with adolescent services. One way of doing this is to conduct a needs assessment of adolescent services currently provided at the health facility (see Module 2).
- Based on findings of the needs assessment, multidisciplinary teams and managers can prioritise key problems and areas for improvement, identify existing human and financial resources, and make a measurable action plan.
- In order to serve adolescent clients with HIV prevention, care, treatment, support and related health services, clinics and programmes must be able to attract, meet the needs of, and retain clients.
- Characteristics of youth-friendly services include important considerations for healthcare workers, the health facility, the way the programme is designed, and the systems that are in place to support adolescent clients over time.
- There are many ways to improve the youth-friendliness of HIV care and treatment services. Additional resources and staff are often not required – and sometimes, even small changes can have a big impact.

## **Key Steps to Initiate or Scale-up Adolescent HIV Care and Treatment Services**

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As you have learned during this training, there are many different aspects involved in the successful provision of HIV care, treatment, and support services for adolescent clients. As you begin to think about how to initiate, integrate, or scale-up adolescent services at your facilities, it is important to keep all of these factors in mind.

As you know from Module 2, there are many things healthcare workers, health facility managers, and youth can do to improve the youth-friendliness of comprehensive HIV care and treatment services. Sometimes, even the smallest adjustments or changes can help — without creating additional workload, or incurring additional costs. Here are some suggestions:

- Conduct a needs assessment of adolescent services currently provided at the health facility. These may be located within a paediatric HIV clinic or in the adult clinic. Do not forget to involve young people in this assessment to ensure their views and opinions are reflected. See Module 2 for more information. The needs assessment should identify existing gaps or problems, based on what you know about the characteristics of a youth-friendly clinic.
- Develop a measurable action plan to prioritise activities that will fill gaps and solve problems. Each action item should have a timeline and the people responsible should be clearly documented. The action plan should also document any other resource needed. Remember, making services youth-friendly does not have to cost a lot of money. Work with what you have!
- Present the action plan to managers, healthcare workers, and youth that will be involved in the programme and regularly revisit the action plan to see what progress has been made and where adjustments are needed.

It is important to remember that setting up youth-friendly HIV care and treatment services is the start – but quality, evidence-based HIV care must be provided within the context of YFS in order to meet the needs of ALHIV.

## **Characteristics of Youth-Friendly Services**

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Recall from Module 2 the discussion of youth-friendly services. The point was made at that time that in order to serve ALHIV with HIV prevention, care, treatment, support and related health services, clinics and programmes must be able to attract, meet the needs of, and retain clients. The clinics that are most likely to attract and retain adolescent clients are those that are youth-friendly. The key characteristics of youth-friendly services, whether they are for HIV, reproductive health, or other types of care are summarised in Table 15.2, below.

**Table 15.2: Characteristics of youth-friendly services**

Healthcare worker characteristics	Health facility characteristics	Programme design characteristics
<ul style="list-style-type: none"> <li>• Specially trained/oriented staff*</li> <li>• All staff display respect for youth</li> <li>• Privacy and confidentiality</li> <li>• Enough time for healthcare worker-client interaction</li> </ul>	<ul style="list-style-type: none"> <li>• Separate space for young people</li> <li>• Special times when young people can receive services</li> <li>• Convenient hours</li> <li>• Convenient location</li> <li>• Adequate space and privacy</li> <li>• Comfortable, youth-friendly surroundings</li> <li>• Availability of Peer Educators</li> </ul>	<ul style="list-style-type: none"> <li>• Youth involvement in programme design and monitoring</li> <li>• Drop-in clients welcomed</li> <li>• Short waiting times</li> <li>• Set up to provide chronic disease management, including multiple appointments and medications</li> <li>• Appointment systems in place and tracking systems for clients who miss appointments</li> <li>• Affordable or no fees for services</li> <li>• Publicity, marketing or recruitment materials that inform and reassure youth</li> <li>• Friendly to both male and female clients</li> <li>• Wide range of services available — “one-stop shopping”</li> <li>• Referrals available to clinical and community-based services</li> <li>• Youth-friendly educational materials available to take away</li> <li>• Youth support groups</li> <li>• Peer educators available</li> </ul>
<p>* Including training in the following areas:</p> <ul style="list-style-type: none"> <li>• Clinical HIV care for adolescents</li> <li>• How to build trust with and counsel adolescents</li> <li>• Providing psychosocial support to adolescents</li> <li>• Mental health assessment, counselling, and referrals</li> <li>• Disclosure counselling</li> <li>• Adherence counselling</li> <li>• Positive living counselling</li> <li>• Sexual and reproductive health counselling and services</li> <li>• Preparing adolescents for the transition to adult care</li> </ul>		

Source: Senderowitz, J., Solter, C., & Hainsworth, G. 2004. *Comprehensive Reproductive Health and Family Planning Training Curriculum. 16: Reproductive Health Services for Adolescents*. Watertown, MA: Pathfinder International.



**Trainer Instructions**

Slide 10

**Step 6:**

Lead participants through Exercise 1, which will give them the chance to work with other participants from their facility to plan and prioritise what needs to be done, and by whom, to improve adolescent HIV services when they return to work.

<b>Exercise 1: Action Planning: Small group work and large group discussion</b>	
<b>Purpose</b>	<ul style="list-style-type: none"> <li>To create an action plan to initiate or improve adolescent HIV care, treatment, and support services at their individual facilities</li> </ul>
<b>Duration</b>	80 minutes
<b>Advance Preparation</b>	<ul style="list-style-type: none"> <li>Review “Appendix 15A: Adolescent HIV Care and Treatment Action Planning and Implementation Template” and make additional copies for participants to write on during the training.</li> <li>Make sure that participants still have a copy of the Youth-Friendly Assessment Tool they started to fill out in Exercise 2, Module 2 (Appendix 2B).</li> </ul>
<b>Introduction</b>	<p>Now that participants are familiar with some of the key steps that need to be accomplished to implement adolescent HIV care, treatment, and support services, give them opportunity work with colleagues to create a site-specific action plan to implement and improve services for ALHIV. Remind participants that this action plan should be achievable and complement any other workplans at their facility.</p>
<b>Activities</b>	<p><b>Small Group Work</b></p> <ol style="list-style-type: none"> <li>1. Break participants into small groups so that healthcare workers from the same facilities are grouped together.</li> <li>2. Ask each small group to assign a facilitator and a notetaker. Give each group extra copies “Appendix 15A: Adolescent HIV Care and Treatment Action Planning and Implementation Template” if needed.</li> <li>3. Ask participants to find the “Checklist and Assessment Tool for Youth-Friendly HIV Care and Treatment Services” from Exercise 2 in Module 2 (Appendix 2B). Participants may want to use this as a starting point for the exercise. Participants should also refer to “Table 2.3: Making services more youth-friendly” for a fuller explanation of the categories listed in the column on the far left.</li> <li>4. Ask each group to spend about 60 minutes discussing and filling in “Appendix 15A: Adolescent HIV Care and Treatment Action Planning and Implementation Template”, thinking about what they want to achieve in the next 6 months. Remind them to think about the specific circumstances at their own facilities as they discuss each section and to be practical — not trying to do too many activities at once and focusing on the activities that will have the most impact on the availability and quality of adolescent HIV services.</li> <li>5. Note that participants should also talk about likely challenges to implementing the action items, and</li> </ol>

	<p>potential solutions to each. There is space to record these potential challenges on the action planning matrix.</p> <p>6. After about 60 minutes, ask the small groups to review their 6-month action plan and to draw a star next to the top 5 priority actions.</p> <p><b>Report Back and Large Group Discussion</b></p> <p>7. Bring the large group back together and ask each small group to give a brief (5 minute) presentation on their small group discussion with a focus on the priority items from their action plan.</p> <p>8. Discuss what the next steps are for the action plans. Participants will likely need to meet again to complete their action plans and solicit inputs from their health facility managers and supervisors.</p> <p>9. Remind participants that the action plans are living documents and that they should be reviewed and updated by the team on a regular basis.</p>
<b>Debriefing</b>	<p>Emphasize that it is important to begin talking about and writing down a specific action plan now while everything learned during the training is still fresh in participants' minds. Reiterate the importance of using the action plan as a living document, and sharing and reviewing the action plan with other healthcare workers, managers, and supervisors for inputs at the start, and on a regular basis thereafter.</p>



**Trainer Instructions**

**Step 7:**

Allow 5 minutes for questions and answers on this session.

## Session 15.2      Reflection on Training Objectives and Concerns, Expectations, and Strengths

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**Total Session Time:**      30 minutes



### **Trainer Instructions**

Slides 11-12

**Step 1:**      Begin by reviewing the session objectives listed below.

### **Session Objectives**

**After completing this session, participants will:**

- Have discussed whether or not the training objectives have been achieved.
- Have reflected on the concerns, expectations, and strengths discussed on the first training day.
- Have listed next steps, including training follow up and supportive supervision.



### **Trainer Instructions**

Slides 13-16

**Step 2:**      Congratulate participants on a job well done. Review the training objectives, listed below. Ask for a volunteer to read each of the learning objectives out loud.

After each, discuss as a group:

- *Did we meet this learning objective during the training?*
- *How confident do you feel that you will be able to do this when you return to your facility?*
- *What extra support would you like in this area?*

Record answers on flip chart, especially areas requiring extra support.



### **Make These Points**

- This training was designed to build the knowledge and skills of multidisciplinary health teams to help them better provide HIV-related care, treatment, and support services to adolescents of different ages and developmental stages.
- There were a number of learning objectives for the training, hopefully most of which we have met.
- Ongoing support, mentoring, and technical assistance will be provided to healthcare workers to help them implement the skills, knowledge, and action plans developed during this training.

## **Adolescent HIV Care and Treatment Training Objectives**

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By the end of this training, participants will be able to:

1. Understand how adolescence differs from childhood and adulthood, and how to ensure HIV-related services are tailored to the special needs of adolescents (youth-friendly).
2. Define the package of HIV-related care and treatment for adolescents.
3. Discuss how to establish trust and rapport with adolescent clients using effective counselling skills.
4. Conduct a psychosocial assessment and provide psychosocial support services to adolescent clients.
5. Screen for major symptoms related to persistent mental illness in adolescents.
6. Provide developmentally appropriate disclosure counselling and support to adolescents and, where appropriate, their caregivers or partners.
7. Identify common barriers to adherence and provide age-appropriate support to prepare adolescent clients and caregivers for adherence and to support adherence to care and medicines over time.
8. Support adolescents to live positively and attain key life skills.
9. Conduct sexual risk screening and sexual risk reduction counselling with adolescent clients as a component of sexual health services.
10. List the contraceptive choices available to ALHIV.
11. Provide an overview of PMTCT services for adolescents living with HIV.
12. Actively link adolescents with facility and community-based support services.
13. Prepare and support adolescents through the transition to adult care.
14. Discuss how information from monitoring and evaluation can be used to support programme improvement.
15. Demonstrate core competencies in adolescent HIV care and treatment services in a clinical setting.
16. Develop a site-specific action plan for implementing adolescent HIV care and treatment services.



## **Trainer Instructions**

Slides 16-18

- Step 3:** Refer to the lists of “Concerns”, “Expectations”, and “Strengths” compiled during the first exercise of Module 1 (“Exercise 1: Getting to know each other: Large group discussion and individual reflection”). The lists of “Concerns”, “Expectations”, and “Strengths” should be posted on the training room wall.
- Ask: *Would anyone like to discuss your current perspective on the “Concerns” that you listed during the “Getting to know each other” exercise?*
  - Review the “Expectations” and compare them with what was actually covered. Note any expectations that were not met and discuss next steps to help ensure that this training need is met in the near future.
  - Reinforce the importance of the “Strengths” that each participant brings to his or her work. Ask if anyone would like to add to the “Strengths” list and note contributions on the flip chart.
- Step 4:** Go around the room and ask each participant to share:
- *What was the most valuable information or skill you learned during the training?*
  - *What is one action that you will prioritise in your work with adolescents living with HIV?*
  - *What is one thing you will take away and share with your co-workers who did not attend this training?*
- Step 5:** Remind participants that, now that the training is over, it is up to each of them to cooperate with other members of their multidisciplinary healthcare teams and to each take the initiative to make sure that their facility-specific adolescent care and treatment action plan is implemented.
- Step 6:** Remind participants that they will be supported to implement their action plans and to improve adolescent care and treatment services over time. Review the plan for supportive supervision and mentoring that will be provided to participants as a follow up to the training.

## Session 15.3 Post-test, Training Evaluation, and Closing



**Total Session Time:** 55 minutes



### **Trainer Instructions** Slides 19-20

**Step 1:** Begin by reviewing the session objectives, listed below.

### **Session Objectives**

**After completing this session, participants will:**

- Have completed the training post-test.
- Have evaluated the training and given suggestions for improvement.



### **Trainer Instructions** Slides 21-46

**Step 2:** Lead participants through the training post-test “Appendix 15B: Post-test”, explaining that it contains the same questions as the pre-test from the first day of training. (Note that the version of the post-test in Appendix 15B of Trainer Manual includes the answers; the version in the Participant Manual does NOT include the answers.)

As you did in Module 1, explain that the objective of the post-test is not to look at individual scores, but rather, to find out what the group as a whole knows about adolescent HIV care and treatment and how much the group’s knowledge has improved from the pre-test. Results of the post-test, and comparison with pre-test scores will help improve future trainings and provide information on ongoing mentoring and supervision needs.

**Step 3:** Point participants to “Appendix 15B: Post-test” in their Manuals. First ask them to write the same number on their post-test as they wrote on their pre-test on Day 1 of the training. If they do not recall this number, then they should turn to the inside front cover of their Participant Manuals, where they should have recorded it on Day 1.

Give participants about 20 minutes to complete the questions

individually. Ask participants to hand their completed post-tests to a trainer when they have finished.

Tell participants that the post-tests will be scored, and then compared to pre-test scores to get a sense of how much they, as a group, have learned.

**Step 4:** After the post-test, debrief by asking participants how they felt answering the questions today compared with the first day of training.

Review the correct answers to each of the questions as a large group.

**Step 5:** Once the training is complete, trainers should:

- Score each post-test, using “Appendix 15B: Post-test” (Trainer Manual version) as a guide. If anyone asks to see their score on the pre-test and/or post-test, let them know how they can do this.
- For each of the 25 questions, calculate how many participants got the answer incorrect. Compare the pre-test scores with the post-test scores, discuss the results with your co-trainers and supervisory, and include the scores and any recommendations in the training report.



**Trainer Instructions**

Slide 47

**Step 6:** Lead participants through Exercise 2, which will give each person a chance to evaluate the training.

<b>Exercise 2: Training Evaluation: Individual work</b>	
<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To get participants’ feedback on the training.</li> </ul>
<b>Duration</b>	15 minutes
<b>Advance Preparation</b>	<ul style="list-style-type: none"> <li>• Refer participants to “Appendix 15C: Training Evaluation Form”.</li> <li>• Refer to “Training Evaluation Form” in “Trainer Manual Introduction Section 3” for additional guidance.</li> </ul>
<b>Introduction</b>	Introduce the training evaluation and encourage participants to give honest feedback (both positive and negative). Tell participants that the trainers will review the evaluation forms carefully and discuss how they can make future trainings better based on the feedback.
<b>Activities</b>	1. After referring participants to “Appendix 15C: Training Evaluation Form” remind participants that they do not have to write their name or position on the form if they

	<p>do not want to, but that it is helpful to provide the name of their facility if they feel comfortable doing so.</p> <ol style="list-style-type: none"> <li>2. Give participants 10–15 minutes to complete the training evaluation. If they did not complete the 2nd section “How helpful were each of the training modules to you and your work? If you have specific comments, please write them on the next page” on an ongoing basis throughout the training, then they might want to refer to their Participant Manuals as a way of refreshing their memory on the content of each of the modules.</li> <li>3. Ask the participants to put their evaluation forms face down in a pile in the front of the room when they are finished.</li> </ol>
<b>Debriefing</b>	<ul style="list-style-type: none"> <li>• Thank participants for their feedback and suggestions and reiterate their importance in improving future trainings.</li> </ul>



### **Trainer Instructions**

Slide 48

- Step 7:** Once again, congratulate participants on a job well done. Present each participant with a training completion certificate (or ask an invited guest to do so).
- Step 8:** If a guest speaker was invited, ask that person to say a few words to close the training. If there is no guest speaker, the trainers can formally close the training.

## Appendix 15A: Adolescent HIV Care and Treatment Action Planning and Implementation Template

Category	What is the specific activity?	Who is responsible?	What resources or support are needed?	When will the action happen?	Means of verification
<b>Conduct a needs assessment of adolescent HIV services currently provided</b>	1.				
	2.				
	3.				
<b>Provide training/ orientation to staff and volunteers</b>	1.				
	2.				
	3.				
<b>Make the health</b>	1.				

<b>facility more friendly to adolescent clients</b>	2.					
	3.					
<b>Involve youth in programme design and service delivery</b>	1.					
	2.					
	3.					
<b>Improve the quality of adolescent clinical care and treatment services</b>	1.					
	2.					
	3.					
<b>Provide “one-</b>	1.					

<b>stop shopping” to adolescent clients</b>	2.						
	3.						
<b>Develop and/or improve appointment and tracking systems</b>	1.						
	2.						
	3.						
<b>Develop peer support programmes and support groups for ALHIV</b>	1.						
	2.						
	3.						

<b>Develop strong referral systems and establish linkages</b>	1.					
	2.					
	3.					
<b>Develop and implement data collection, reporting, monitoring, and evaluation systems</b>	1.					
	2.					
	3.					

**Anticipated challenges to implementing the adolescent HIV care and treatment action plan and possible solutions**

Anticipated Challenge	Possible Solution(s)
1.	
2.	
3.	
4.	
5.	

## Appendix 15B: Post-test

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**NOTE: This version is for trainer only. Correct answers are in bold.**

Participant identification number: \_\_\_\_\_ Score: \_\_\_\_/25

- 1) Which of the following statements are factors in the scale up of adolescent HIV care and treatment services in Zambia? **(select all that apply)**
  - a) Young people are no more vulnerable to HIV than adults.
  - b) Youth living with HIV face unique health, adherence, and psychosocial issues and challenges.**
  - c) Healthcare workers need specific knowledge and skills to meet the needs of adolescent clients.**
  - d) Programmes and clinical services need to be youth-friendly to attract and retain adolescent clients**
  
- 2) Which of the following are characteristics of “youth-friendly” services? **(select all that apply)**
  - a) Special times that allow young people to receive services**
  - b) Services are provided anonymously.
  - c) Healthcare workers are friendly to both male and female clients**
  - d) Clinic services are affordable or available for no fees**
  - e) Healthcare workers create services without the input of adolescents
  
- 3) To be effective, the adolescent package of care must ensure: **(select all that apply)**
  - a) Integration of services**
  - b) That services are age and developmentally appropriate**
  - c) That the needs of both perinatally infected adolescents, as well as those infected later in childhood or adolescence**
  - d) That services are empowering, in other words, they encourage adolescents to take responsibility for their own health**
  - e) That the adolescent client receives care in the paediatric clinic for life
  
- 4) The key clinical components of care for ALHIV differ greatly from care of adults.
  - a) True
  - b) False**
  
- 5) Adolescent clients should be started on ART when their CD4 cell count is:
  - a) Less than 200
  - b) Less than 250
  - c) Less than 300
  - d) Less than 350**
  - e) None of the above

- 6) CD4 cell count should be monitored how frequently?
- a) Every 12 months; but 6 monthly as CD4 count approaches threshold (to initiate ART)
  - b) Every 9 months; but 4 monthly as CD4 count approaches threshold
  - c) Every 6 months; but 3 monthly as CD4 count approaches threshold**
  - d) Every 4 months; but 2 monthly as CD4 count approaches threshold
  - e) Every 2 months; but monthly as CD4 count approaches threshold
- 7) Healthcare workers can use the 5 “A’s” when providing clinical and psychosocial care and support to clients. What are the 5 “A’s”?
- a) Assess, admire, agree, ask, arrange
  - b) Analyze, advise, agree, ask, arrange
  - c) Assess, advise, agree, assist, arrange**
  - d) Assess, advise, assert, ask, arrange
  - e) Awake, advise, agree, ask, arrange
- 8) Counselling includes which of the following? (select all that apply)
- a) Solving another person’s problems
  - b) Helping people to make informed decisions**
  - c) Telling another person what to do
  - d) Respecting everyone’s needs, values, culture, religion, and lifestyle**
  - e) Keeping good records**
- 9) Family-centred care means that healthcare workers can talk openly with caregivers about any information shared between the adolescent and healthcare workers.
- a) True
  - b) False**
- 10) Which of the following are coping strategies that healthcare workers should suggest to clients and caregivers to help them reduce stress and promote psychosocial well-being? (select all that apply)
- a) Talk with a Peer Educator**
  - b) Join a support group**
  - c) Exercise**
  - d) Disclose HIV status to all people in the community
  - e) Change your environment and take a walk**
- 11) Adolescence is a unique stage of life that is characterised by:
- a) Challenging caregivers or elders
  - b) Focus on body image
  - c) Sense of immortality
  - d) Significant physical, emotional, and mental changes
  - e) All of the above**

- 12) Which of the following are signs or symptoms of depression? (**select all that apply**)
- a) **Hopelessness**
  - b) Shaking and sweating
  - c) **Really tired with no energy**
  - d) Heart pounding fast
  - e) **Do not enjoy the things you used to (loss of interest or pleasure)**
  - f) **Sleep too much or not enough**
  - g) **Cannot eat or eat too much**
  - h) Cannot breathe or shortness of breath
- 13) Disclosure is a one-time event, rather than an ongoing process.
- a) True
  - b) **False**
- 14) The process of disclosing HIV status to an adolescent with HIV should include discussion of the following:
- a) The diagnosis, the infection and disease process, and health changes that could occur.
  - b) Strategies to prolong a healthy life (in particular adherence to ART) and responsibilities now and in the future.
  - c) How to cope with the possible negative reactions of others.
  - d) A and C
  - e) **All of the above**
- 15) The Zambia “Adult and Adolescent Antiretroviral Therapy Protocols, 2010” recommends a minimum of 3 adherence preparation visits, as part of a structured treatment preparation plan prior to initiating ART.
- a) **True**
  - b) False
- 16) The only reliable way to assess client adherence is with pill counts.
- a) True
  - b) **False**
- 17) What is positive prevention? (**select all that apply**)
- a) **Partner disclosure and testing**
  - b) Sleeping and resting under an insecticide-treated mosquito net if in a malarial area
  - c) **Sexual risk reduction and sexual health**
  - d) **Prevention and treatment of STIs**
  - e) Bathing regularly
  - f) **PMTCT**
  - g) **Prevention of blood-borne HIV transmission, including transmission through injecting drug use, sharing sharp instruments to cut or pierce the skin.**

- 18) What questions would you ask to screen for alcohol dependency?  
(select all that apply)
- a) **Have you ever felt that you should cut down on your drinking?**
  - b) **Have people annoyed you by criticising your drinking?**
  - c) Have you ever found it difficult to wake up for school or work?
  - d) **Have you ever felt bad or guilty about your drinking?**
  - e) Have you ever experienced rapid heartbeat after drinking?
  - f) **Have you ever had an eye-opener — a drink first thing in the morning to steady your nerves or get rid of a hangover?**
- 19) Which of the following statements is correct?
- a) Healthcare workers need to stress that only heterosexual behaviour is NORMAL
  - b) **Healthcare workers need to stress that homosexual, bisexual, and transsexual/transgendered behaviour is NORMAL**
  - c) Healthcare workers need to stress that homosexual, bisexual, and transsexual/transgendered behaviour is ABNORMAL
  - d) Healthcare workers need to stress that transsexual/transgendered should not be tolerated
- 20) The following sexual activities are considered *high* risk for transmitting HIV: (select all that apply)
- a) **Unprotected (no male or female condom) anal or vaginal intercourse**
  - b) Sharing sexual toys (rubber penis, vibrators) without cleaning them
  - c) Using a male or female latex condom for every act of sexual intercourse (penis in vagina, penis in anus, penis in mouth, etc.)
  - d) Mutual masturbation
  - e) Oral sex without a latex barrier
- 21) The adolescent female genital tract is more biologically susceptible to STIs than that of older women.
- a) **True**
  - b) False
- 22) What advice would you give an ALHIV who wanted to get pregnant?  
(select all that apply)
- a) **It is safest to wait until adulthood to become pregnant**
  - b) Do not eat eggs while pregnant
  - c) **Talk to your provider and ask for his/her advice**
  - d) **Make sure you do not have any opportunistic infections**
  - e) **Make sure you are adhering to your ART regimen**

- 23) Which of the following are good family planning options for ALHIV? **(select all that apply)**
- a) **Condoms**
  - b) **Combined oral contraceptive pills (COCs), progestin-only oral contraceptive pills**
  - c) Spermicides and diaphragms with spermicides
  - d) Male and female sterilisation
  - e) **Hormonal implants**
- 24) In reference to transitioning to adult care, which of the following statements is true? **(select all that apply)**
- a) Clients should be transitioned to adult care by 18 years of age
  - b) **In preparing to transition, the healthcare worker should support the adolescent to develop self-care and self-advocacy skills**
  - c) **In preparation to transition, adolescents should visit and tour the adult clinic**
  - d) Adolescent clients should be encouraged to rely more and more on their caregivers to ensure they adhere to their ART regimen
- 25) Which of the following are examples of indicators? **(select all that apply)**
- a) **Number of adolescents who initiated ART**
  - b) **Number of adolescents currently receiving ART**
  - c) To ensure that 95% of eligible adolescent clients initiate ART.
  - d) To ensure that at least 120 new clients initiate ART in the next 3 months
  - e) To ensure loss to follow up is no more than 5%

## Appendix 15C: Training Evaluation Form

Name (optional): \_\_\_\_\_

Your position (optional): \_\_\_\_\_

Health facility where you work (optional): \_\_\_\_\_

**INSTRUCTIONS:** Please rate the following statements on a scale of 1 to 5.

	☹ Strongly Disagree	Disagree	Neither agree nor disagree	Agree	☺ Strongly Agree
1. The training objectives were clear.	1	2	3	4	5
2. This training met my expectations.	1	2	3	4	5
3. The technical level of this training was appropriate.	1	2	3	4	5
4. The pace of this training was appropriate.	1	2	3	4	5
5. The facilitators were engaging and informative.	1	2	3	4	5
6. The information I learned in this training will be useful to my work.	1	2	3	4	5
7. I am confident that after this training, my facility will be able to provide HIV-related care, treatment, and support services to adolescents.	1	2	3	4	5

How helpful were each of the training modules to you and your work? If you have specific comments, please write them on the next page.

	☹ Not helpful				☺ Very helpful
Module 1: Introduction and Course Overview	1	2	3	4	5
Module 2: The Nature of Adolescence and Provision of Youth-Friendly Services	1	2	3	4	5
Module 3: Clinical Care for Adolescents Living with HIV	1	2	3	4	5
Module 4: Communicating with and Counselling Adolescents	1	2	3	4	5
Module 5: Providing Psychosocial Support Services for Adolescents	1	2	3	4	5
Module 6: Adolescents, HIV, and Mental Health	1	2	3	4	5
Module 7: Providing Disclosure Counselling and Support	1	2	3	4	5
Module 8: Supporting Adolescent's Retention in, and Adherence to, HIV Care and Treatment	1	2	3	4	5
Module 9: Positive Living for Adolescents	1	2	3	4	5
Module 10: Sexual and Reproductive Health Services for Adolescents	1	2	3	4	5

Module 11: Community Linkages and Adolescent Involvement	1	2	3	4	5
Module 12: Supporting the Transition to Adult Care	1	2	3	4	5
Module 13: Monitoring, Evaluation, Quality Assurance, and Supportive Supervision	1	2	3	4	5
Module 14: Supervised Clinical Practicum	1	2	3	4	5
Module 15: Action Planning, Course Evaluation, and Closure	1	2	3	4	5

**What was the best part of this training?**

**How can we improve this training?**

**Other comments:**

**Thank you for your participation, and for your commitment to adolescents and families in Zambia!**

